

**Facilitators and Barriers to Physical Activity Experienced and Perceived by Adults  
with Intellectual Disability**

by

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## THESIS EXAMINATION INFORMATION

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An oral defense of this thesis took place on November 29, 2019 in front of the following examining committee:

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The above committee determined that the thesis is acceptable in form and content and that a satisfactory knowledge of the field covered by the thesis was demonstrated by the candidate during an oral examination. A signed copy of the Certificate of Approval is available from the School of Graduate and Postdoctoral Studies

## ABSTRACT

Adults with intellectual disability (ID) experience high rates of health conditions that can be prevented and improved through health-promoting behaviours; however, they engage in considerably low levels of physical activity, the reasons for which are often multi-faceted and not always self-evident. This study utilized qualitative phenomenological inquiry, grounded in both the interpretivist and transformative paradigms, to explore the perspectives of adults with ID (n=13) of facilitators and barriers to their physical activity. Two focus groups were guided by semi-structured interview questions. Thematic analysis produced four facilitator themes (*Individual, Support, Programs, Resources*) and three barrier themes (*Internal, External, and Not Recognizing or Understanding Barriers*). The results suggest that adults with ID face a number of facilitators and barriers to their physical activity, which often act in combination to influence participation. Understanding these factors can lead to the development and implementation of well-informed strategies to increase physical activity in this population.

**Keywords:** intellectual disability; physical activity; adults; facilitators; barriers

## AUTHOR'S DECLARATION

I hereby declare that this thesis consists of original work of which I have authored. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

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The research work in this thesis was performed in compliance with the regulations of Ontario Tech's Research Ethics Board/Animal Care Committee under **REB Certificate number /Animal care certificate file number 15240.**

Shannon Lucas

## **STATEMENT OF CONTRIBUTIONS**

I hereby certify that I am the sole author of this thesis and that no part of this thesis has been published or submitted for publication. I have used standard referencing practices to acknowledge ideas, research techniques, or other materials that belong to others. Furthermore, I hereby certify that I am the sole source of the creative works and/or inventive knowledge described in this thesis.

## **DEDICATION**

I dedicate my thesis to the most important person in my life, my older sister, Reanna. We may sometimes be one another's greatest nuisance, but what else are sisters for?

Thank you for your understanding, support, and resiliency.

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## LIST OF ABBREVIATIONS

ID	intellectual disability; intellectual disabilities
TD	typical development; typically developing
IQ	Intelligence Quotient
GTA	Greater Toronto Area
AAIDD	American Association on Intellectual and Developmental Disabilities
WHO-ICF	World Health Organization's International Classification of Functioning, Disability, and Health

## **OVERVIEW**

This thesis is divided into five chapters:

1. Introduction
2. Literature Review
3. Manuscript
4. Conclusions
5. Appendices

## **CHAPTER 1. INTRODUCTION**

## 1. Introduction

### 1.1 Overview of Intellectual Disabilities

Intellectual disabilities (ID) are a subgroup of neurodevelopmental disorders characterized by: (a) limitations in intellectual functioning, (b) limitations in adaptive functioning (in the conceptual, social, and practical domains), and (c) onset during developmental years (American Association on Intellectual and Developmental Disabilities, 2010; Batshaw, Roizen, & Lotrecchiano, 2013; Tassé, Luckasson, & Schalock, 2016). Historically, an Intelligence Quotient (IQ) score that is “approximately two standard deviations below the mean” has been used as the criterion alongside clinical judgement to help diagnose ID (American Association on Intellectual and Developmental Disabilities, 2010, p. 35). It is important to note that *developmental disability* and *learning disability* are two terms sometimes used interchangeably with ID (Tassé, 2016). There are two recognized classification systems that are used to diagnose the “level” of ID. The older classification is based on the severity of functional limitations, with categories ranging from “mild”, “moderate”, “severe”, to “profound” (Batshaw et al., 2013; Elinder, Bergström, Hagberg, Wihlman, & Hagströmer, 2010; Katz & Lazcano-Ponce, 2008). An updated classification system, proposed in 1992 by the *American Association on Intellectual and Developmental Disabilities* (AAIDD) (named the *American Association on Mental Retardation* at the time), is based on level of support required by the individuals with ID (rather than on severity of deficits); it comprises four categories: “intermittent”, “limited”, “extensive”, and “pervasive” (Batshaw et al., 2013; Wehmeyer, 2003). A single definitive definition, term, and classification system have yet to be agreed upon and universally used (Crawford, 2011).

The prevalence of ID has been estimated to be between 1-3% of the world's population, and varies depending on the country and criteria used to diagnose it (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). In the province of Ontario, approximately 0.5% of the population have an ID (Bielska, Ouellette-Kuntz, & Hunter, 2012; Crawford, 2011; The Institute for Clinical Evaluative Sciences, 2013). This translates to approximately 67,000 Ontarian adults utilizing the health and social service systems (The Institute for Clinical Evaluative Sciences, 2013). Research has revealed that adults with ID experience high rates of health and mental health conditions (Cooper et al., 2015) and this has resulted in higher rates of service utilization compared to those with typical development (TD), indicating that this population's health status does not only affect the individuals with ID, but it also negatively impacts the public health and social systems they use and rely on (Balogh, Hunter, & Ouellette-Kuntz, 2005; Dunn, Hughes-McCormack, & Cooper, 2018; Krahn, Hammond, & Turner, 2006).

The generally poorer health status seen throughout the ID population is attributed to a number of factors, but a lack of health-promoting activities is a key determinant (Doody & Doody, 2012). Healthy diet, regular health screening, and regular physical activity are examples of health-promoting activities, all of which contribute to a lower risk of disease and prolonged life expectancy (Melville, Hamilton, Hankey, Miller, & Boyle, 2007). In particular, scientific evidence indicates that participation in frequent physical activity at moderate to vigorous intensities is important for sustained physical and psychosocial health for all people, including people with ID (Temple & Stanish, 2008). However, research consistently shows that physical activity levels in the ID population are significantly lower than in the TD population (Dairo, Collett, Dawes, &

Oskrochi, 2016; Finlayson, Turner, & Granat, 2011). Therefore, increasing physical activity is a vital component of improving the overall health and wellbeing of persons with ID (Bergström, Hagströmer, Hagberg, & Elinder, 2013; Robertson et al., 2000).

## **1.2 Health and Physical Activity in the Intellectual Disability Population**

Physical activity is defined as any bodily movement that is produced by skeletal muscles and requires energy expenditure (World Health Organization, n.d.). Participating in physical activity on a regular basis has been shown to lead to a number of physical, psychological, and social benefits for all people, with and without ID (Carraro & Gobbi, 2012; Warburton, Nicol, & Bredin, 2006). Conversely, a physically inactive lifestyle has been shown to lead to detrimental effects on health over time (Dairo et al., 2016). Despite the knowledge of the critical role that physical activity plays in the maintenance of health and well-being, research tells us that those with ID, especially adults, exhibit significantly lower rates of physical activity compared to those without ID (Hsieh, Heller, Bershadsky, & Taub, 2015; Stancliffe & Anderson, 2017; Taliaferro & Hammond, 2016; van Schijndel-Speet, Evenhuis, van Wijck, van Empelen, & Echteld, 2014). The reasons behind this trend are complex and wide-ranging (Frey, Buchanan, & Sandt, 2005; Messent, Cooke, & Long, 1999; Temple & Walkley, 2007). Oftentimes, it is a multifaceted combination of both individual and environmental factors that influence the ability to be physically active (Bodde & Seo, 2009; Bossink, van der Putten, & Vlaskamp, 2017). Therefore, uncovering facilitators and barriers to physical activity perceived and experienced by adults with ID is an “important prerequisite for designing relevant policies and effective programs” (Shibata, Oka, Harada, Nakamura, & Muraoka,

2009 p. 1) that will potentially lead to more physical activity and thus improved health status for these individuals.

### **1.3 Facilitators and Barriers to Physical Activity for People with Intellectual Disability**

In the context of physical activity, facilitators are anything that act to make it possible or easier to participate (Cambridge English Dictionary, n.d.-b), while barriers are anything that act to inhibit a person from participating (Cambridge English Dictionary, n.d.-a). Facilitators and barriers exist for all people in the pursuit of physical activity (Pan et al., 2009). No matter one's ability, age, living situation, or health status, it can be challenging to be active on a regular basis (Pan et al., 2009). However, individuals with ID are a unique group with a unique set of barriers, which must be addressed and overcome in order for them to pursue healthy behaviours (Bossink et al., 2017). Understanding the factors that hinder (*barriers*) and promote (*facilitators*) physical activity has the potential to guide future strategies, interventions, programs, and policies.

The literature on the topic of facilitators and barriers to physical activity for adults with ID has revealed the existence of both individual and environmental factors, citing such things as personal preference or motor limitations, all the way to transportation availability or program opportunities (Alesi, 2017; Barr & Shields, 2011; Bergström, Elinder, & Wihlman, 2014; Bossink et al., 2017; Cartwright, Reid, Hammersley, & Walley, 2016; Mahy, Shields, Taylor, & Dodd, 2010). Previous research has shown that adults with ID who report many barriers to physical activity tend to be more sedentary, while those who report fewer barriers tend to be more active (Temple, 2007). This indicates that barriers have an influence on a person's ability to be active and shows that

the removal of barriers may help to facilitate physical activity for this population (Bossink et al., 2017). Exploring the factors that are facilitating participation in physical activity, and those that are preventing it, is a crucial task to undertake.

#### **1.4 Research Question**

This study aims to explore the following research question: *What are the facilitators and barriers to physical activity experienced and perceived by adults with intellectual disability?*

#### **1.5 Purpose and Significance**

In order to address a problem, it is necessary to first understand the root causes of that problem. This is why research on facilitators and barriers is an important antecedent to interventions and to program and policy amendments (Seefeldt, Malina, & Clark, 2002; Shibata et al., 2009). Exploring facilitators and barriers to physical activity for adults with ID expands the foundation of knowledge upon which future research and changes can occur.

This study aims to contribute to the body of literature on the facilitators and barriers to physical activity that exist for the adult ID population. The participants will provide valuable insight into their experiences and perspectives on the factors influencing their own physical activity participation. By interviewing these individuals, knowledge can be gained on the common physical activity influences experienced by adults with ID living within the Greater Toronto Area (GTA) in the province of Ontario, Canada. The results have the potential to inform people, programs, organizations, policies, interventions, and services, which could thus lead to improvements in the physical activity and health of individuals with ID.

## 1.6 Theoretical Framework

A *paradigm*, otherwise known as a *worldview* or *philosophical approach*, is defined as a basic set of beliefs that guide action (Guba, 1990). In research, paradigms direct the researcher toward different approaches based on the views they hold. This study is designed around *interpretivist* and *transformative* paradigms. An *interpretivist* paradigm (also known as *social constructivist* paradigm) describes a philosophical approach that frames a study in such a way that the participants' subjective experiences are represented in a comprehensive way that expands – rather than simplifies – the meaning of those experiences (Creswell & Poth, 2018). Interpretivist researchers recognize and appreciate the complexity of subjects and are often interested in those complex variables (Creswell & Poth, 2018). This paradigm is in stark contrast to *postpositivism*, which is a type of paradigm that studies subjects removed from their worlds, so as to simplify variables and control for bias (Creswell & Poth, 2018). Interpretivism often takes form in qualitative methodology because of the role that *interpretation* plays in data analysis. It explores the lived experiences (e.g. facilitators and barriers) of people (e.g. adults with ID) within the world in which they live and work (Creswell & Poth, 2018).

Transformativism is a philosophical approach that advocates for marginalized groups, such as those with ID (Creswell & Poth, 2018). This paradigm takes into account societal, political, and historical powers and struggles and has the ultimate objective of improving the lives of the individuals and groups being studied (Creswell & Poth, 2018). The approach is dialectical and emancipatory in nature (Creswell & Poth, 2018), and while this study does not necessarily have an action agenda, approaching this research

topic with a goal for reform, in policy or otherwise, is important to its success. Therefore, methodology will contain aspects of both the interpretivist and transformative paradigms.

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## **CHAPTER 2. LITERATURE REVIEW**

## **2. Literature Review**

### **2.1 Historical Societal Views of Intellectual Disability**

Leading up to the 1980's, disabilities of all kinds were viewed in a similar way to disease, in that if they could not be treated or fixed, there was largely nothing that could be done to improve the lives of individuals with disabilities (Goering, 2015). This “traditional” approach, or perspective of treatment, is representative of the medical model of disability, which focuses only on the limitations of the disability (‘internal deficits’) and fails to take the environment’s role into account (Emerson & Hatton, 2014; Goering, 2015). With the adoption of the social model of disability over recent decades, disabilities themselves are no longer viewed as a limiting factor; rather, factors external to the individual (environmental and societal structures) are understood as playing a decisive role in the disability, such as how they can aggravate or alleviate the effects of the disability (Emerson & Hatton, 2014; Pariseau-Legault & Holmes, 2015). The adoption of the social model represents progress in how society views and accommodates people with disabilities.

The change in the definition and classification system of ID also represents a shift in ideology. The older classification system (mild, moderate, severe, profound) uses stigmatizing language that focuses on impairment alone (American Association on Intellectual and Developmental Disabilities, 2010). However, Wehmeyer (2003) posits that the 1992 classification system (intermittent, limited, extensive, pervasive levels of support) is a “significant departure” (p. 272) from previous conceptualizations of ID because it caused those in the field to consider it as a “function of the relationship among individual functioning, supports, and contexts” as opposed to viewing it as a defect of the

individual (p. 276). These conceptualizations of disability are important when examining the facilitators and barriers to physical activity for adults with ID because it helps us understand disability through its complex interaction with multiple internal and external factors acting in combination to create specific disadvantages or opportunities for these individuals.

The positive shift in ideological conceptualizations of ID has been mirrored in the increasingly progressive societal attitudes toward enhanced human and disability rights (Davis, Fox-Grage, & Gehshan, 2000; Lemay, 2009; Parish, 2005). From the 1960's through to the 2000's, policy reform saw the deinstitutionalization movement take place in Canada and the United States, gradually moving thousands of people with ID from long-stay institutions into supportive homes in the community (Chowdhury & Benson, 2011; Emerson & Hatton, 1996; Parish, 2005). In Ontario, the last institution closed in 2009, and all of those individuals with ID have now found homes situated in neighbourhoods and communities (Lemay, 2009). Research has shown that individuals with ID have benefited and continue to benefit from community living in a number of ways; compared to the time spent in institutions, individuals with ID who had transitioned into community settings were shown to participate in more activities, receive more time and attention from support providers, experience improvements in social skills and adaptive functioning, and experience declines in challenging behaviour (Emerson & Hatton, 1996; Lemay, 2009). They also displayed improvements in self-care skills (Lemay, 2009). Institutions offered limited social opportunities, and the move into the community saw more consistent social contact and connectedness, especially with family members (Lemay, 2009; Spreat & Conroy, 2002). The literature shows that the positive

effects of community living (such as greater individualized care, more opportunities for socialization, and more choices for leisure activities) have led to improved overall quality of life for individuals with ID (Chowdhury & Benson, 2011; O'Brien, Thesing, Tuck, & Capie, 2001). Wider society has also benefitted from the deinstitutionalization movement, as there is evidence that the costs of living and care are lower when individuals live within the community than when they live in institutions (Lemay, 2009).

Although deinstitutionalization has provided many benefits, there have been, perhaps unforeseen, negative consequences to individuals with ID. Increased independence has meant increased responsibility over health-related lifestyle decisions (Bodde, Seo, & Frey, 2009; de Winter, Bastiaanse, Hilgenkamp, Evenhuis, & Echteld, 2011). While this is not inherently problematic, research has shown that adults with ID living in the community are more susceptible to higher rates of chronic, preventable health conditions, like obesity and cardiovascular disease, which researchers have attributed to both increased independence and challenges overcoming environmental barriers (Bodde et al., 2009; de Winter, Bastiaanse, Hilgenkamp, Evenhuis, & Echteld, 2012; Draheim, 2006). Adults with ID typically have difficulty with such things as money management, personal care, and health care (components of adaptive functioning) (American Association on Intellectual and Developmental Disabilities, 2010); this means that the independence gained by living in the community may make them vulnerable to take up unhealthy habits, like poor diet and low physical activity (Cocks, Thomson, Thoresen, Parsons, & Rosenwax, 2018). By consequence of deinstitutionalization, there was also an increased demand for the development and expansion of specialized community services to meet the needs of this population (Parish, 2005). There is

evidence that, despite progress, health services within the community may not be as readily accessible as they were in institutions (e.g. transportation difficulties, appointment scheduling), which can potentially result in less frequent care and therefore poorer health status for individuals with ID (Chowdhury & Benson, 2011). However, over the last few decades, as societal structures and services have been adjusting to the transition of persons with ID into the community, there have been advancements in their opportunities to access appropriate services, participate in leisure activities, and experience a better sense of inclusion in their communities (Amado, Stancliffe, McCarron, & McCallion, 2013). Overall, the progressive shift in both the societal perspective of ID and the treatment of persons with ID has led to clear improvements in their quality of life since deinstitutionalization (Parish, 2005).

## **2.2 Etiology of Intellectual Disabilities**

The etiology of ID is not always well understood. There are many causes of ID and they can occur due to factors relating to chromosome mutation, hereditary diseases, congenital exposure to toxins or infectious diseases, trauma to the brain, as well as environmental and cultural factors affecting development, such as poverty (Katz & Lazcano-Ponce, 2008). Overall, individuals with ID are a very heterogenous group with heterogenous needs (Peterson, Janz, & Lowe, 2008). According to the American Association on Intellectual and Developmental Disabilities (AAIDD) (2010), identifying the etiology of an individual's ID can tell us "a great deal about that person's actual, potential, and future support needs" (p. 69). In some cases, knowing the etiology of an individual's ID can play a role in the health status and health and social services potentially needed across their lifetime (American Association on Intellectual and

Developmental Disabilities, 2010). For example, Down syndrome is a condition caused by a genetic error that almost always results in ID, and it has been shown to be linked to a higher prevalence of obesity, diabetes, heart defects and conditions, intestinal defects, hearing difficulties, thyroid conditions, and early-onset dementia and menopause, when compared to those with typical development (TD) and those with other ID etiology (Katz & Lazcano-Ponce, 2008; Pikora et al., 2014). In many cases, understanding the type of disability can lead to improved outcomes relating to an individual's health, support, education, and life-planning (American Association on Intellectual and Developmental Disabilities, 2010). Regardless of disability etiology, the health of individuals with ID is significantly poorer than persons with TD (Cocks et al., 2018; Haverkamp & Scott, 2015).

### **2.3 Health Status of People with Intellectual Disability**

'Preventable' diseases, also referred to as 'secondary' or 'non-communicable' diseases, are conditions that can be largely prevented, or at least mitigated or delayed, by healthy lifestyle habits, such as regular physical activity, healthy nutrition, and regular health screenings (Krahn, Hammond, & Turner, 2006). According to a 2011 study, adults with ID were considerably more likely to have Type 2 diabetes, arthritis, cardiovascular disease, and asthma, compared to adults without disabilities (Krahn & Fox, 2014; Reichard, Stolzle, & Fox, 2011). Many preventable conditions that are disproportionately experienced by persons with ID (high blood pressure, high cholesterol, stroke, and overweight/obesity) are not causally linked to their disability (Krahn & Fox, 2014; Reichard et al., 2011). This suggests that there is a high probability that poor health is at least somewhat related to unhealthy lifestyle behaviours, like poor nutrition and physical

inactivity, rather than from the inherent traits of the disability (Caton et al., 2012; Krahn & Fox, 2014).

Comorbidities are defined as co-occurring conditions existing at one time in one person, and are chronic and separate (Cooper et al., 2015; Krahn et al., 2006). The prevalence of comorbidities and multi-morbidities is significantly higher in the ID population; it has been reported as being as high as 80% (Hermans & Evenhuis, 2014). The rate at which these individuals seek out or require practitioner care is also exceptionally high (Ouellette-Kuntz et al., 2005). Canadian adults with ID experience mental illness (commonly referred to as dual diagnosis) at a rate of between 30-45% (Bielska, Ouellette-Kuntz, & Hunter, 2012). Individuals with ID are also prescribed psychotropic medications at a higher rate than is seen in the general population (Ouellette-Kuntz et al., 2005). There is strong evidence that regular participation in physical activity benefits mental health in the general population, such as preventing and alleviating the symptoms of anxiety and depression as well as improving mood, sleep, and ability to concentrate (Mikkelsen, Stojanovska, Polenakovic, Bosevski, & Apostolopoulos, 2017). In research involving individuals with ID, challenging behaviours, such as aggression and self-injury, were also seen to significantly decrease following exercise interventions (Ogg-Groenendaal, Hermans, & Claessens, 2014). In many cases in the general population, physical activity cannot fully replace the use of psychotropic medication, but when used in combination, it has been shown to be effective at improving mental health (Mikkelsen et al., 2017). Given the poly-pharmacology common to adults with ID for treating mental illness, physical activity may be a viable option for promoting mental health (Ogg-Groenendaal et al., 2014).

However, there is a need for further research on the mental health benefits of physical activity on adults with ID.

Research reveals that individuals with ID frequently experience disparities in the health and social care they receive (Balogh, Lake, Lin, Wilton, & Lunskey, 2015; Krahn & Fox, 2014; Ouellette-Kuntz, 2005; Reichard et al., 2011). Not only do adults with ID have more difficulty accessing appropriate health and social services than do adults without ID, they have more difficulty than do children with ID, due to both increased complexity of care and aging out of paediatric health services (Certo et al., 2008; Hudson, 2006; Osgood, Foster, & Courtney, 2010; Singh, 2009). This is troubling because adults often have higher needs than children and adolescents because of their age-related conditions (Haveman et al., 2010; Janicki et al., 2002). Adults with ID utilize medical and social services at a disproportionately high rate, and as life expectancy continues to rise, there will be even more adults with ID utilizing these public systems and contributing to high costs (Dairo, Collett, Dawes, & Oskrochi, 2016). However, compared to adults with TD, individuals with ID are less likely to reach the country's life expectancy (by an average of 10-15 years) (Bittles et al., 2002; Ouellette-Kuntz et al., 2005). Along with preventable conditions, this population experiences limitations and impairments in vision, hearing, gastrointestinal function, and mobility at higher rates than those with TD (Bodde & Seo, 2009; Haveman et al., 2010; Ouellette-Kuntz et al., 2005). This makes health care decisions and involvement in one's own health-promoting behaviour a primary concern (Doody & Doody, 2012) for adults with ID, the people that care for them, and the systems that serve them.

Having access to appropriate health and social services is essential for the treatment and management of health and mental health conditions. However, it should be considered as equally essential to have access to opportunities that help promote health and prevent disease, especially for this high-risk population (Doody & Doody, 2012; Lloyd, 2016). Physical activity is a common form of health promotion that has been shown to improve health conditions and increase quality of life for individuals with and without disabilities (Bartlo & Klein, 2011; Canadian Society for Exercise Physiology, 2011), so enhancing physical activity opportunities for adults with ID could have a positive, meaningful impact on health.

#### **2.4 Physical Activity and Intellectual Disability**

In recent years, Canada has taken an initiative to implement disease prevention and health promotion strategies [such as the creation of the Centre for Health Promotion, Canada's Food Guide, Canadian Physical Activity Guidelines, and investments in health promotion research projects (Public Health Agency of Canada, 2018)] as a way to reduce incidence of secondary conditions and to lower health care costs for future generations (Ouellette-Kuntz et al., 2005). Regular physical activity is an important factor contributing to overall health and well-being of individuals with and without disabilities (Bartlo & Klein, 2011; Heller, Mccubbin, Drum, & Peterson-Besse, 2011); it not only helps to prevent and improve chronic conditions, it has a positive effect on aerobic capacity, weight, skeletal muscle strength, gross motor function, balance and coordination, age-related declines, maladaptive behaviours, psychosocial well-being, and overall quality of life (Heller et al., 2011; Stancliffe & Anderson, 2017). Therefore, it is

of the utmost importance that healthy lifestyle habits, such as physical activity, be as accessible as possible for adults with ID.

In 2010, the government of Canada released a set of specific guidelines for physical activity based on research that has examined the positive effects it has on health and well-being (Canadian Society for Exercise Physiology, 2011; Tremblay et al., 2011). For adults aged 18-64, the population of interest for this thesis, it is recommended that they accumulate at least 150 minutes per week of moderate-to-vigorous physical activity in bouts of 10 or more minutes, with 2 days of strength training (Canadian Society for Exercise Physiology, 2011; Tremblay et al., 2011). Evidence indicates that this recommended amount and intensity is protective against chronic, preventable conditions, such as obesity, cardiovascular disease, respiratory disease, type 2 diabetes, oral disease, and mental illness, among others (Bodde & Seo, 2009; Eisenberg, Vanderbom, & Vasudevan, 2016; Taliaferro & Hammond, 2016). In a 2006 review that discussed the relationship between physical activity and chronic conditions, it was found that a dose-response existed: higher levels of regular physical activity are associated with lower risk for the development of chronic, preventable conditions (Warburton et al., 2006). While no guidelines exist specifically for adults with ID, these guidelines for the general population act as a benchmark.

In a study by Hsieh, Hilgenkamp, Murthy, Heller, & Rimmer (2017), adherence to recommended physical activity levels was examined in the United States using the National Core Indicators Survey. They found that only 13.4% of adults with ID were reaching the recommended level (Hsieh et al., 2015). Another study by Stancliffe and Anderson (2017), that collected data two years later using the same survey tool, found a

similar rate of 13.5% adherence to the guidelines. This study also considered the physical activity adherence rate of adults with TD and discovered that they attain the recommended physical activity levels at more than twice the rate, at 30.5% (Stancliffe & Anderson, 2017). While large-scale surveys are generally dependable standards of measurement for gathering statistical information, surveys of such magnitude may fail to capture accurate numbers due to respondent over-estimates; one study found that fewer than half of the participants with ID accurately reported their physical activity when compared to their actual physical activity measured by pedometers (Finlayson, Turner, & Granat, 2011). This suggests that physical activity levels reported by this population may actually be even lower in reality. A 2016 systematic review by Dairo et al., which looked at 15 studies comprising over 3000 participants combined, found that an average of only 9% of the adults with ID actually reached the recommended levels of physical activity. A 2013 study by Barnes et al. found that adults with ID were falling significantly short of meeting the weekly recommended physical activity level, with 26% of the sample of 131 participants reporting taking part in *no* physical activity at all (Barnes et al., 2013). It is also important to note that most physical activity opportunities for this sample were incidental (not a purposeful decision to be active), such as walking to and from work and doing chores (Barnes et al., 2013). When a population demonstrates such consistently low levels of physical activity, the reasons why become all the more important to determine.

Adults with ID experience similar, if not higher, rates of health conditions that are often associated with a sedentary lifestyle, compared to adults with TD (Bodde & Seo, 2009; Taliaferro & Hammond, 2016). One reason for such a high prevalence of these

conditions is due in part to limitations in adaptive functioning; the ability to understand and manage time, money, and self-care activities affects an individual's capacity to make appropriate health decisions, manage illness and disease, and pursue healthy leisure time activities (American Association on Intellectual and Developmental Disabilities, 2010).

In general, research has revealed that adults with ID have limited knowledge of the benefits of regular physical activity and other disease prevention strategies which makes them vulnerable to low motivation to participate in them (Caton et al., 2012; Jobling & Cuskelly, 2006). A 2012 study by Caton et al. investigated the knowledge of individuals with ID and found that while almost all participants had an understanding of what it meant to be healthy, very few could explain what it meant to be unhealthy. Almost all the participants were able to describe examples of physical activity and their previous physical activities, but the authors point out that many of the participants described participation "in a more idealistic way" and provided references to activities in which they no longer participated (Caton et al., 2012, p. 253). This study sheds light on how lack of knowledge can play a hindering role in the physical activity participation of adults with ID. In a scoping review by Heller et al. (2011), the authors examined studies on physical activity and nutrition interventions and programs for persons with ID, including cardiorespiratory, flexibility, strength, and balance training, as well as health education classes and health screenings. They found that physical activity and other health-promoting interventions can have positive effects on health, such as improved fitness and wellbeing, and improved or mitigated symptoms of chronic conditions (Heller et al., 2011). However, the authors emphasize that disparities exist in "the ability to develop, implement, and sustain programs and health benefits over time" (Heller et al., 2011, p.

34). In other words, although regular physical activity has benefits for individuals with ID, there are many barriers to participation, and there is a need for better physical activity strategies.

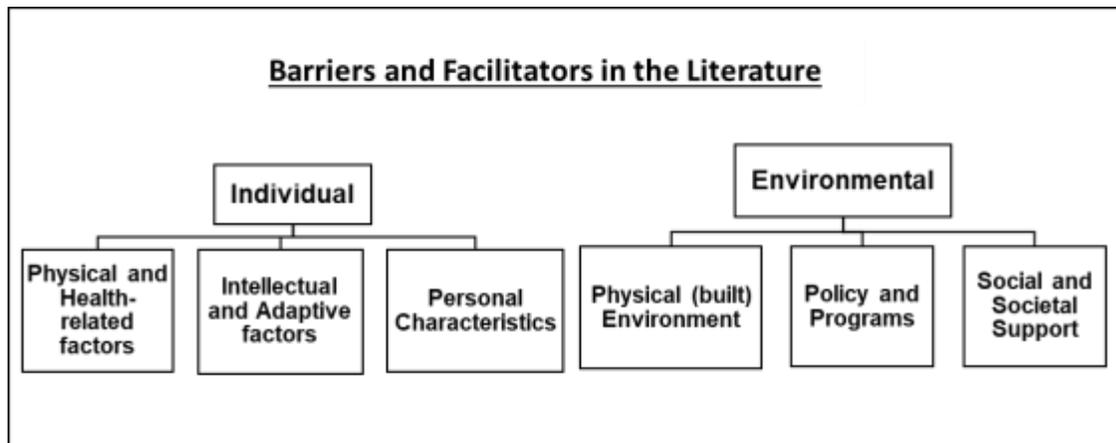
## **2.5 Facilitators and Barriers to Physical Activity: Adults with Intellectual Disability**

In order for adults with ID to become more physically active, the factors influencing their opportunities for physical activity must be understood and addressed (Taliaferro & Hammond, 2016). If interventions and policies do not adequately draw on facilitators and anticipate barriers, they will likely not be effective at what they aim to do (Krahn & Drum, 2007). A thorough understanding of the factors influencing physical activity can lead to effective planning and reform to improve participation (Krahn & Drum, 2007).

Over recent decades, there has been a gradual shift in health care ideology that is moving away from disease treatment and toward health promotion (Lloyd, 2016; Rimmer, 1999; Rimmer & Braddock, 2002). Research has both influenced and been influenced by this shift and is reflected in the increased research interest in facilitators and barriers to physical activity (Barr & Shields, 2011; Bodde & Seo, 2009; Bossink, van der Putten, & Vlaskamp, 2017; Mahy, Shields, Taylor, & Dodd, 2010; Stancliffe & Anderson, 2017; Taliaferro & Hammond, 2016; Temple & Walkley, 2007; van Schijndel-Speet, Evenhuis, van Wijck, van Empelen, & Echteld, 2014). A large majority (greater than 80%) of adults with ID are not participating sufficiently in sport and exercise (Barnes et al., 2013; Dairo et al., 2016; Hsieh et al., 2017; Stancliffe & Anderson, 2017; Temple, Frey, & Stanish, 2006). Researchers have studied the factors influencing the low levels of physical activity in people with and without ID and the results from these

studies provide insight into how we as a society can increase physical activity. According to the literature, physical activity is influenced by a number of factors, both intrinsic to the individual and those occurring in the external environment (Bodde et al., 2009; Bossink et al., 2017; Taliaferro & Hammond, 2016; Temple & Walkley, 2007; van Schijndel-Speet et al., 2014).

Studies approach the concept of facilitators and barriers to physical activity with varying aims, participant types, and methods, and have thus contributed to this expanding field of research. Both qualitative and quantitative studies present findings that usually organize results into larger categories, such as individual and environmental facilitators and barriers (American Association on Intellectual and Developmental Disabilities, 2010). In this way, it is easier to conceptualize and discuss the factors influencing physical activity (Figure 1).



*Figure 1.* A conceptual organization of facilitators and barriers to physical activity for adults with ID found in the literature. Adapted from multiple sources: American Association on Intellectual and Developmental Disabilities, 2010; Bodde & Seo, 2009; Bossink et al., 2017; Temple & Walkley, 2007; World Health Organization, 2002.

### 2.5.1 Individual Facilitators and Barriers

Depending on the level of intellectual and adaptive functioning, level of support required, health status, personal characteristics, and living situation, the way in which adults with ID participate in physical activity and experience facilitators and barriers can be quite different from person to person (Melville, Hamilton, Hankey, Miller, & Boyle, 2007; Peterson et al., 2008). However, many studies in this area have broadened the scope of information that can be applicable to many persons with ID. Individual facilitators and barriers can be divided even further into more specific subcategories: physical and health-related, intellectual and adaptive factors, and personal characteristics (see Figure 1).

**Individual: Physical Factors.** Included in this subcategory are factors such as physical characteristics, bodily structures and functions, motor skills and abilities, health conditions, and age (World Health Organization, 2002). In terms of personal abilities, an individual's level of competency or skill was cited as a factor in physical activity participation by both caregivers and individuals with ID (Barr & Shields, 2011; Bossink et al., 2017). Individuals with ID reported that, if an activity was too difficult for them or if they did not know how to play a sport, they would choose not to participate (Burk & Sharaievska, 2017). It was also reported that adults with ID feel they should not be participating for fear of sustaining injury, exacerbating health conditions, or not being fit enough to keep up (Bodde & Seo, 2009; Bossink et al., 2017; Bowers et al., 2016). Increased age was reported as a barrier, while younger age was a facilitator (Bossink et al., 2017). Physical discomfort during participation was also reported to be a barrier

(Bossink et al., 2017). These are physical factors that derive from the individual which contribute to the success of one's ability to be physically active.

**Individual: Intellectual and Adaptive Factors.** In accordance with the definition of ID, intellectual functioning refers to a person's ability to reason, plan, problem-solve, think abstractly, comprehend complex ideas, learn quickly, and learn from experience (American Association on Intellectual and Developmental Disabilities, 2010). Adaptive functioning refers to reading, writing, managing money and time (conceptual domain); social responsibilities, social problem-solving, self-esteem, gullibility, obeying rules/laws, avoiding being victimized (social skills domain); personal care, safety, health care, use of money, travel, and schedules/routines (practical domain) (American Association on Intellectual and Developmental Disabilities, 2010). Cognitive abilities are often reported as a barrier by caregivers (Alesi, 2017). Individuals with ID often reported the planning aspects of physical activity as a barrier. Specifically, planning activities and the details of such activities, such as transportation and timing, were challenging for persons with ID (Burk & Sharaievska, 2017). Difficulties with communicating, concentrating, and understanding were also reported as barriers (Barr & Shields, 2011; Burk & Sharaievska, 2017). This is reflected in the common caregiver-reported need to increase the availability of smaller, more adapted physical activity programs, in order to facilitate learning and participation (Alesi, 2017).

**Individual: Personal Characteristics.** Personal characteristics include such things as an individual's attitude toward physical activity, preferences,

motivation, and sociability (Bossink et al., 2017) and are closely tied to personality. An important contributing factor to the level of physical activity that any person achieves is often directly due to their level of enjoyment of the activity, and adults with ID are no different (Barr & Shields, 2011; Taliaferro & Hammond, 2016; Temple & Walkley, 2007). Enjoyment and motivation are two commonly-reported influences of physical activity, both as facilitators and barriers (Burk & Sharaievska, 2017, 2017; Taliaferro & Hammond, 2016; Temple & Walkley, 2007). External rewards (such as medals and ribbons commonly awarded to Special Olympics athletes) were also identified as facilitators (Bossink et al., 2017; Bowers et al., 2016). This indicates that efforts made to enhance enjoyability and pride through rewards may increase physical activity participation in this population. Poor social skills, on the other hand, were identified as being barriers to physical activity (Bossink et al., 2017), and contribute to a cycle of exclusion and poor social skills. Level of self-efficacy is strongly related to the decision to pursue physical activity; participants who report feeling confident in their physical activity abilities tend to also report higher levels of physical activity (Bergström, Elinder, & Wihlman, 2014; Bossink et al., 2017; Temple & Walkley, 2007). There is also the factor of personal preference as both a facilitator and a barrier, whereby adults with ID who prefer to partake in sedentary activities have a more difficult barrier to overcome in order to become physically active (Bossink et al., 2017). Self-determination and increased autonomy were both reported as facilitators, as adults with ID report that having the opportunity to take part in the planning of their own activities increases their

likelihood to participate (Bergström et al., 2014; Bossink et al., 2017). A high level of competition was often reported as a barrier by adults with ID (Bodde & Seo, 2009; Bowers et al., 2016), indicating that less-competitive physical activity environments may be more appealing to individuals with ID to participate in. Research shows that adults with ID experience factors that can either facilitate or impede physical activity, and many of those factors are, or can be, within their control. Facilitators and barriers that relate to the body, personality, or disability are important to consider when implementing interventions or designing programs that aim to improve physical activity levels.

### **2.5.2 Environmental Facilitators and Barriers**

The physical, social, and political/attitudinal environments can all act to influence the ability to be active in persons with TD (World Health Organization, 2002). Financial constraints to physical activity, low staffing, and poor weather were some of the most prominent environmental barriers to engagement in physical activity for adults with ID (Bossink et al., 2017), while social support networks and activities having elements of fun were the most prominent environmental facilitators (Bossink et al., 2017). These facilitators are so frequently reported that they should be taken into serious consideration when planning physical activity programs and policies. Environmental facilitators and barriers can be divided even further into more specific subcategories: physical (built) environment, policy and programs, and social and societal support (see Figure 1).

**Environmental: Physical (Built) Environment Factors.** In terms of the built environment, factors that relate to residence and the community can influence physical activity in both individuals with and without ID (Eisenberg et al., 2016).

The geographical location of an individual's residence and the structure and size of the community often affects their ability to travel to gyms, playing fields, and parks (Abbott & McConkey, 2006; Eisenberg et al., 2016). Being close to a bus route is also a very commonly-reported factor influencing travel to and from these places (Abbott & McConkey, 2006; Eisenberg et al., 2016). Residential location has been shown to closely relate to the unavailability of transportation in general. If an individual relies on caregivers for rides or supervision for navigating public transport, this can negatively impact their ability to be active when they want to be active (Bossink et al., 2017; Bowers et al., 2016). The physical resources within a residence can also play a part in a person's ability to be active (Dixon-Ibarra, Driver, Vanderbom, & Humphries, 2017; Howie et al., 2012). In a study by Howie et al. (2012) that specifically examined physical activity resources in the home, there were fewer than 40% in a sample of 103 individuals with ID who had access to sports equipment, and even fewer who had access to exercise equipment. The authors concluded that although there are a multitude of correlates to physical inactivity, the tangible availability of physical activity equipment could potentially introduce more opportunities to be more active (Howie et al., 2012). A lack of time (realized here as a physical barrier external to the individual), whether real or perceived, is a very commonly-cited barrier for individuals with ID, parents, caregivers, and paid support staff (Bossink et al., 2017; Burk & Sharaievska, 2017; Taliaferro & Hammond, 2016). Time constraints were most often due to work and other social obligations that

prevented adults with ID from regularly taking time out of their week to be physically active (Taliaferro & Hammond, 2016).

**Environmental: Policy and Program Factors.** Policies and programs created and regulated by organizations, agencies, ministries, and governments are a sub-category of environmental factors that can influence physical activity for adults with ID. They have been reported as playing an impactful role in whether or not an individual with ID is regularly physically active (Taliaferro & Hammond, 2016). Bowers et al. (2016) found that Special Olympics programs acted as the main, or only, opportunity to participate in physical activity and socialize with peers, indicating a lack of program choice for people with ID. Agency, organization, and sometimes government budgets dictate the staffing, frequency, and affordability of physical activity programs, and more often than not, act as barriers instead of facilitators due to lack of resources overall (Cartwright, Reid, Hammersley, & Walley, 2016; Taliaferro & Hammond, 2016). As mentioned, a person's financial circumstances also greatly affect physical activity participation; this relates to the ability to purchase exercise and sport equipment, enroll in a physical activity program or purchase a gym membership, and also relates to travel expenses (Bossink et al., 2017; Bowers et al., 2016; Burk & Sharaievskaya, 2017; Melville et al., 2009; Temple & Walkley, 2007). Adults with ID are generally more likely to experience lower socioeconomic status and live in poverty, and research has shown that a lack of financial resources can often have a negative impact on one's ability to be sufficiently physically active (Anderson et al., 2013). The unaffordability of some programs force individuals with ID to be

active in other ways, such as neighbourhood walking, which is a form of exercise that usually does not occur at a moderate-to-vigorous level of energy expenditure (Dixon-Ibarra et al., 2017).

Individuals and groups with ID can reach out to local organizations and business for sponsorship, such as to participate in Special Olympics competitions, and this prospect for funding was reported as a facilitator in one study (Bowers et al., 2016). However, unaffordability is a commonly-cited barrier, as is the general lack of programs (Barr & Shields, 2011; Bowers et al., 2016; Taliaferro & Hammond, 2016). This relates to information dissemination about programs; Taliaferro and Hammond (2016) found that most caregivers find out about physical activity opportunities via word of mouth. Having knowledge about programming is a facilitator because programs may not be adequately advertised or accessible to parents, caregivers, and adults with ID; however, a lack of knowledge about program options is also regularly reported as a barrier (Barr & Shields, 2011; Bossink et al., 2017; Burk & Sharaievska, 2017; Taliaferro & Hammond, 2016). Parents and caregivers report having minimal knowledge about how clubs are run, where they are located, who is eligible to participate, and how to register, and this lack of clarity has a negative impact on physical activity participation for the individual with ID (Bowers et al., 2016). Meanwhile, structured and accessible physical activity programs with appropriate guidance, encouragement, and adapted activities are commonly reported facilitators to physical activity (Barr & Shields, 2011; Bossink et al., 2017).

It is very common for adults with ID at a transition age (adolescence into adulthood) to have to deal with “aging out of supports” (Taliaferro & Hammond, 2016). Both adults with ID and their parents/caregivers report that a lack of programs becomes a reality. Due to age restriction policies and a limited number of adult programs in place, adolescents with ID who are aging into adults with ID, become ineligible for youth programs, which leaves them at a loss for activity choice (Taliaferro & Hammond, 2016). Caregivers also discuss a lack of support from secondary schools once they graduate (Taliaferro & Hammond, 2016). For those who do have physical activity programs available to them, parents report apprehension about whether the program is suitable for their adult children, stating that having information about programs would ease registration (Bowers et al., 2016). Managers, support staff, and parents mentioned the importance of having “an established link person” or “main point of contact” to assist in connecting to and navigating physical activity services (Bowers et al., 2016, p. 365) which indicates a need for better-organized systems. Programs that are lacking in volunteers or staff, lacking in skilled and experienced instructors, are overly competitive, are non-inclusive, and get regularly cancelled, are frequently-cited barriers to physical activity participation for individuals with ID (Bossink et al., 2017; Bowers et al., 2016; Cartwright et al., 2016). In addition to this, programs are also limited in the variety of activities they can offer, due to the heterogeneity of the population and concerns over ensuring everyone can participate (Cartwright et al., 2016), which can lead to disinterest in more-capable individuals. There is also a trend in social service programming toward more

sedentary activities, like cooking and crafting, because the activities are reported as being selected based on the skillsets of the staff rather than being catered toward the service users (Cartwright et al., 2016). Programs, or particularly a lack thereof, are a major factor in the low levels of physical activity seen in the adult ID population. Researchers suggest that agencies serving this population develop well-informed physical activity policies and programs as a function of health promotion and disease prevention (Temple & Walkley, 2007).

**Environmental: Societal and Social Support Factors.** Social and societal factors are a form of environmental facilitators and barriers which include such factors as amount and type of support, role modeling, and others' attitudes, all of which influence an individual's ability to be physically active (Bossink et al., 2017). A very commonly-reported influence of physical activity for adults with ID is the role of support persons (Abbott & McConkey, 2006; Bossink et al., 2017; Temple & Walkley, 2007). Parents and caregivers play an influential role in the lives of the individuals they care for and can be the deciding factor in which activities these individuals participate (Abbott & McConkey, 2006). In other words, if a caregiver does not promote physical activity, it is possible the person with ID will not get the opportunity to be active. Family and caregivers are often the decision-makers for these individuals and that can be quite limiting to their opportunities to socialize and participate in the leisure-time activities of their choosing, especially as autonomous adults (Cartwright et al., 2016). Thus, family availability, leadership, and engagement impact on an individual's physical activity (Barr & Shields, 2011; Cartwright et al., 2016). There is a consistent need

for family commitment to ensure that the individual with ID remains active as they age, but this may leave less time for other family members' activities and responsibilities, forcing caregivers to spread out their commitments (Bowers et al., 2016). Parental and caregiver time constraints are often reported as a major barrier to physical activity for individuals with ID (Bossink et al., 2017; Cartwright et al., 2016; Melville et al., 2009). Caregivers also report experiencing emotional and mental burnout that can lead to difficulties in providing consistent support to these individuals (Taliaferro & Hammond, 2016). Family members' own physical activity behaviour also has an influence on an individual's interest in pursuing physical activity because they are often seen as role models (Barr & Shields, 2011). The same can be said for paid support staff. It is interesting to note that parents and support workers tend to report the facilitating role of their own support, while individuals with ID tend to more-regularly report their role as a limiting influence; a lack of support, skills, knowledge, and interest from their caregivers are significant barriers for adults with ID (Bossink et al., 2017; Cartwright et al., 2016; Melville et al., 2009; Temple & Walkley, 2007). For individuals with ID who experience comorbidities and/or physical limitations, parents and staff admit to having apprehension over their ability to safely participate and enjoy themselves, which is another barrier to physical activity participation (Bossink et al., 2017). A sense of camaraderie was reported as a facilitating factor for physical activity participation; adults with ID describe that feelings of acceptance, safety, and motivation from peers facilitate more regular participation in physical activity (Taliaferro & Hammond, 2016). In a study by

Bowers et al. (2016), Special Olympics participants stated that they felt a sense of purpose and belonging when taking part in their respective sports. Therefore, social opportunities, when embedded in physical activities, appear to have the potential to act as both a facilitator to, and a positive effect of, physical activity participation.

Cartwright et al. (2016) found that caregivers and/or support staff generally assumed that individuals with ID did not care to be active or were limited by their abilities to be active and therefore did not prioritize physical activity for them. The researchers also found that there was a belief by some family caregivers that the responsibility for improving and maintaining physical activity participation fell more on paid support staff and program staff than on themselves (Cartwright et al., 2016). However, the researchers found that this often resulted in neither the staff nor the family caregivers taking responsibility (Cartwright et al., 2016). It has also been found that a high level of collaboration of caregivers, day centre staff, and other organizations help to facilitate physical activity (Bergström et al., 2014), but this collaboration is rare and imperfect. Understanding the importance of communication and where it tends to deteriorate can help program and policy creators plan for a more collaborative approach to improving the physical activity opportunities for adults with ID.

Advocacy, inclusion, freedom from judgement, and positive community attitudes are positively correlated with increased levels of physical activity because of the feeling of acceptance and support to participate in activities outside of the home (Abbott & McConkey, 2006; Bowers et al., 2016). In the literature,

people with ID have reported encouragement as one of the most meaningful and influential forms of support for physical activity engagement (Bossink et al., 2017).

It is clear from a review of the literature that adults with ID face a multitude of barriers in accessing, participating in, and maintaining physical activity. Researchers have also identified various useful facilitators that can help to alleviate challenges and overcome those barriers. Programs, interventions, and education that build from this evidence may have the potential to positively impact the physical activity and health of the lives of adults with ID. It is important to note, however, that, while many facilitators and barriers to physical activity are unique to the ID population, there are some that are shared by those without disabilities.

## **2.6 Facilitators and Barriers to Physical Activity: Adults in the General Population**

Similar to adults with ID, adults with TD can often experience difficulties in regularly participating in physical activity at the recommended levels (Shibata, Oka, Harada, Nakamura, & Muraoka, 2009; Stancliffe & Anderson, 2017). Multiple studies have determined that only around 30% of adults with TD are attaining the recommended levels of physical activity to prevent or mitigate chronic health conditions (Shibata et al., 2009; Stancliffe & Anderson, 2017). While these levels of physical activity are relatively low, they are still considerably greater than the levels attained by adults with ID, which is around 13% (Stancliffe & Anderson, 2017). Nonetheless, adults with TD still experience numerous facilitators and barriers to regularly participating in physical activity (Granner, Sharpe, Hutto, Wilcox, & Addy, 2007; Shibata et al., 2009). The literature identifies various internal and external factors that have an influence on adults' ability to become

and remain physically active. Some commonly-reported individual barriers to physical activity for adults with TD include old age, poor health, low self-esteem, minimal interest/motivation, and unhealthy habits (Giles-Corti & Donovan, 2002; Seefeldt, Malina, & Clark, 2002). Some commonly-reported external (both social and environmental) facilitators to physical activity for adults with TD include close proximity to physical activity facilities, encouragement from family and friends, and having an exercise partner (Granner et al., 2007; Li et al., 2016). As the above evidence shows, the facilitators and barriers to physical activity for adults with TD are not unlike those for adults with ID.

In Giles-Corti and Donovan's (2002) analysis of the determinants of physical activity for people with TD, they found that the main influences of physical activity were individual (internal) factors – *not* environmental or social (external) factors. This is a particularly noteworthy finding when compared to persons with ID; while persons with TD experience mainly individual barriers to their physical activity, adults with ID experience barriers across the domains of individual, social, and environmental. This is an interesting contrast because it illustrates the lack of control that adults with ID often have over their own physical activity compared to those without disabilities. In a study conducted on Canadian adults without ID, the researchers found that social support did not significantly affect physical activity (Pan et al., 2009). This is also especially noteworthy because this finding contrasts what is commonly reported by persons with ID, which is that social support is one of the most impactful facilitators to their physical activity (Bossink et al., 2017; Emerson & Hatton, 2014). This reinforces the notion that the physical activity of individuals with ID may be disproportionately influenced by

external factors beyond their control than individual factors within their control. In a paper by Haskell, Blair, and Hill (2009), the authors conclude that, given the evidence of physical activity providing many health benefits, it is necessary to implement major policies and programs focused on health promotion, especially for those people who are inactive and unfit. The authors make a point of emphasizing that the effects of low levels of physical activity appear to be independent of factors such as race/ethnicity, income, education, and body size (Haskell, Blair, & Hill 2009), meaning a lack of physical activity is unhealthy for all people, likely including people with ID. The authors also lay out a set of broad areas on which to focus health-promotion efforts in the general population, including: education about health risks associated with low physical activity levels, lifestyle changes, improvements to physical activity opportunities within schools and workplaces, improvements to the built environment of communities to better facilitate physical activity, and increases in prioritization of physical activity through government funding (Haskell, Blair, & Hill 2009). Although health promotion strategies are important for improving the health of all people, most public health-promotion efforts are targeted toward the general public, and often overlook special populations with unique needs, such as persons with ID (Emerson & Hatton, 2014). Their design and/or poor information dissemination can make them inaccessible to groups most in need of health-promoting activities (Emerson & Hatton, 2014). This being said, these recommendations made for health promotion in the general population can act as a foundation for health promotion efforts in the ID population.

## **2.7 Gaps in Knowledge, Implications, and Future Directions**

This literature showed that there is still knowledge to be gained about the facilitators and barriers to physical activity for adults with ID. As we gain more insight, we can begin to improve, progress, and create appropriate avenues for physical activity promotion and maintenance (Lloyd, 2016). In fact, authors highlight the importance of this type of research, with Brooker et al. (2015) discussing the necessity for research into facilitators and barriers before considering planning for any type of physical activity intervention.

Individuals with ID have historically been excluded from the research that directly concerns them (Horner-Johnson & Bailey, 2013). One of the reasons this occurs is because they may be perceived as not having the intellectual capacity to participate meaningfully, or that they are not able to provide consent to participate (Horner-Johnson & Bailey, 2013). However, research in recent years has included individuals with ID much more than it used to (Bossink et al., 2017). Future research should continue on this route of inclusion.

It is also pertinent to note that Bossink et al. (2017) found that studies often focus on and/or discover more barriers than they do facilitators. This demonstrates a direction in this area of research that has prioritized the removal of barriers ahead of the implementation of facilitators. Since facilitators are the factors that improve physical activity, it is immensely important that future researchers focus as much attention as possible on them as they do barriers.

In a paper by Stanish and Frey published a decade ago (2008), they state that there is a limited body of research in the area of facilitators and barriers to physical activity for

adults with ID. They discuss the difficulty of measuring a phenomenon with multiple and complex variables and instead posit the usefulness of qualitative studies in describing the reasons behind low levels of physical activity (Stanish & Frey, 2008). Since then, many researchers have followed suit and the body of literature has more than doubled.

However, Taliaferro and Hammond (2016) alluded that facilitators and barriers can often be specific to geographical locations and unique populations. This means that research evidence from previous studies may not necessarily be applicable to other regions.

Therefore, conducting this research in the Greater Toronto Area (GTA) of Ontario, Canada has the potential to eventually positively affect the physical activity of tens of thousands of individuals with ID who reside there, and who may be at-risk for preventable health conditions.

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## **CHAPTER 3. MANUSCRIPT**

### **The Facilitators and Barriers to Physical Activity from the Perspectives of Adults with Intellectual Disability**

### 3. Manuscript

#### 3.1 Abstract

**Background and Purpose:** Adults with intellectual disabilities (ID) are not meeting the physical activity levels required to maintain good health and fitness. As a population that experiences disproportionately high levels of preventable health conditions, a health-promoting strategy like physical activity becomes important. However, research has shown that this population experiences a unique set of challenges that makes it difficult to be active. Therefore, it is necessary to identify the factors that influence their physical activity in order to overcome barriers and facilitate participation. This study's objective was to explore the facilitators and barriers to physical activity for adults with ID living in the Greater Toronto Area (GTA).

**Methods:** This phenomenological study employed two focus groups with adult participants with ID (n=13), who were recruited separately from two adult day programs. Semi-structured interview questions centred around participants' experiences with physical activity. Both focus groups were audio-recorded and their data was transcribed verbatim, coded in NVivo, and thematically analyzed.

**Results:** Four facilitator themes emerged: the individual, the support they receive, the programs they attend, and the resources they access. Three barrier themes emerged: internal influences, external influences, and difficulty with recognizing barriers.

**Conclusions:** Adult participants with ID reported a variety of facilitating and hindering influences of their physical activity, adding to the current body of literature. Future research should aim to build upon this knowledge so that effective physical activity strategies, interventions, and programs can continue to be developed for this population.

## **3.2 Introduction**

### **3.2.1 Physical Activity in Adults with Intellectual Disability**

Adults with intellectual disability (ID) experience significantly higher rates of physical and psychological health conditions compared to those with typical development (TD) (Cooper et al., 2015). Many of the conditions that they experience are ‘preventable’, meaning they could be prevented, mitigated, or delayed if a person was to take up and maintain a healthier lifestyle, inclusive of frequent health screenings, nutritious eating, and accruing regular physical activity (Doody & Doody, 2012). However, research shows that adults with ID are not taking up or maintaining healthy lifestyles. Physical activity is an important strategy for promoting good health and preventing diseases (Warburton, Charlesworth, Ivey, Nettlefold, & Bredin, 2010), but previous researchers have identified that it may be more difficult for those with ID to access physical activity (Anderson et al., 2013; Hsieh et al., 2017). This population faces a number of barriers that are not faced by the general population, many of which relate to the characteristics of their ID (e.g. comprehension skills), and many of which also relate to the built environment and wider society (e.g. transportation assistance) (Bartlo & Klein, 2011; Bossink, van der Putten, & Vlaskamp, 2017). Health promotion strategies have become increasingly important across society (Havercamp & Scott, 2015) and are expressly important for populations that are at risk of experiencing high rates of preventable health conditions, such as those with ID (Melville, Hamilton, Hankey, Miller, & Boyle, 2007).

Research has revealed that physical activity levels in the ID population are significantly lower than in the general population (Dairo, Collett, Dawes, & Oskrochi, 2016; Finlayson, Turner, & Granat, 2011). A 2017 study by Stancliffe and Anderson

found that 13.5% of adults with ID were physically active, which is less than half as active as adults with TD (30%). The Canadian Physical Activity Guidelines recommend that an adult acquire 150 minutes of moderate-to-vigorous physical activity per week (Canadian Society for Exercise Physiology, n.d.), but the evidence is unequivocal; on average, adults with ID do not come close to reaching these levels.

Within Ontario, Canada, there are approximately 67,000 adults with an ID (Ouellette-Kuntz, Shooshtari, Balogh, & Martens, 2015; The Institute for Clinical Evaluative Sciences, 2013), many of whom are likely not reaching the recommended levels of physical activity needed for the maintenance of good health. Adults with ID access health care services at disproportionately high rates (Balogh, Hunter, & Ouellette-Kuntz, 2005; Dunn, Hughes-McCormack, & Cooper, 2018; Krahn, Hammond, & Turner, 2006), and efforts to enhance health promotion and disease prevention strategies can lead to subsequent reductions in health care system utilization (Krahn et al., 2006). In order to achieve such reductions, researchers must first examine the complex factors influencing the physical activity of the adult ID population in the Greater Toronto Area (GTA) of Ontario.

### **3.2.2. Facilitators and Barriers to Physical Activity**

Over recent years, much attention has been paid to the topic of health and health promotion in people with ID, and there is a growing number of studies that have examined facilitators and barriers to physical activity (Bodde & Seo, 2009; Bossink et al., 2017; Mahy, Shields, Taylor, & Dodd, 2010; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004; Taliaferro & Hammond, 2016; Temple & Walkley, 2007; van Schijndel-Speet, Evenhuis, van Wijck, van Empelen, & Echteld, 2014). In the pursuit of

physical activity, there are naturally a variety of facilitators and barriers that exist for all people, both with and without ID (Pan et al., 2009). In the general population, it has been found that adults who report more barriers are less likely to be active (Salmon, Owen, Crawford, Bauman, & Sallis, 2003). The same has been found in research with adults with ID (Temple, 2007). However, adults with ID are in an especially vulnerable position because many of the barriers they experience are not easily modified or resolved (Lloyd, 2016). Their dependency on others for practical support (e.g. transportation, financial) is also a unique barrier that is not usually experienced by adults with TD (Bossink et al., 2017).

Bossink et al. (2017) conducted a systematic review of 24 qualitative and quantitative studies that investigated facilitators and barriers to physical activity for people with ID. They organized factors into two overarching categories, 'Personal' and 'Environmental'. Some factors were more commonly reported among the studies, and some were more unique, indicating both a universality to the experience of facilitators and barriers, and more uncommon, specific experiences. Some prominent personal facilitators and barriers that were identified relate to health issues, physical abilities, social interaction, self-motivation, and preference (Bossink et al., 2017). Some prominent environmental facilitators and barriers that were identified relate to transportation, family support, staff support, activity options, and weather (Bossink et al., 2017). The variety of findings indicate that some facilitators and barriers are perhaps more commonly experienced than others, and this justifies the need for studies to explore the universality of the experience and to investigate if there are any specific facilitators and barriers experienced by different populations of adults with ID.

The literature presents a wide array of facilitators and barriers to physical activity that have been identified by adults with ID and proxy reporters (Bodde & Seo, 2009; Bossink et al., 2017). Gaining a further understanding of these factors can ultimately lead to the implementation and improvement of strategies, interventions, programs, and policies that impact the physical activity levels of this population. In fact, one study found that identifying barriers is one of the most important factors for positively affecting health behaviour change and health promotion interventions for individuals with ID (Willems, Hilgenkamp, Waninge, & Melville, 2017). It is therefore vital to first examine the facilitators and barriers that affect physical activity levels in this population, before the problem of low physical activity can begin to be capably addressed.

This manuscript is divided into the following sections: Introduction, Methods, Results, and Discussion. The Introduction includes background information and the purpose of the research. The Methods section covers procedures of participant recruitment, and data collection and analysis. The Results section comprises the findings acquired through procedures of code-counting and thematic analysis. Lastly, the Discussion includes a reflection on the findings, strengths and limitations of the study, implications and directions for future research, and final conclusions.

### **3.2.3 Purpose and Research Question**

The purpose of this study was to explore *the facilitators and barriers to physical activity as experienced and perceived by adults with intellectual disabilities*. By interviewing adults with ID, the primary stakeholders of this research, this study represents their experiences and, in doing so, places them at the centre of the research that directly concerns them.

### **3.3 Methods**

#### **3.3.1 Study Design**

This qualitative study utilized a phenomenological theoretical framework. The defining feature of phenomenology is the ability to capture the common meaning, or the “universal essence”, of lived experiences (Creswell & Poth, 2018, p. 75). In this study, the phenomenon that was explored were the factors influencing physical activity, and inactivity, in the adult ID population. This approach recognizes the interplay of the subjectivity and objectivity of the participants and their experiences with physical activity and its facilitators and barriers; this means that their experiences were understood as their subjective realities in reference to an objective phenomenon (Creswell & Poth, 2018). Two semi-structured focus groups were conducted.

#### **3.3.2 Participants and Recruitment**

An idiographic sampling approach was employed (Robinson, 2014). Idiographic sampling is an approach taken to obtain a small but sufficient sample with a focus on studying individual cases, rather than large, representative samples (Robinson, 2014; Sim, 2001). This aligns with the interpretivist paradigm used to frame this study, in which individual experiences are expanded rather than simplified (Creswell & Poth, 2018). Because the aim is to perform a relatively intensive analysis of each participant’s contribution and to ensure each participant has an identity within the study (‘whole person’ representation), there was a sample size of 13 individuals (Robinson, 2014). Participants (n=13) were attendees of two separate adult day programs, organized by two separate community organizations. These organizations support the wellbeing of adults with ID by providing supportive, educational, leisure-time opportunities which may not

otherwise be available to them. One adult day program was designed to provide opportunities for adults with disabilities to experience social interaction, recreation and leisure activities, animal and nature engagement, and to learn important life and self-care skills. The other adult day program was designed to provide opportunities for adults with disabilities to experience a variety of activities in the areas of sport and fitness, the arts, socializing, and life skills.

The recruitment process began by contacting service directors of two programs. An explanatory invitation email was sent to the respective directors, which was followed by a meeting in which the principal investigator further explained the study and confirmed their interest to allow program attendees to be approached for possible participation. The directors, acting as gatekeepers into the organization, recruited service users on the principal investigator's behalf. The principal investigator was able to meet with some of the potential participants ahead of time, which helped to develop rapport, something that is especially important for successful recruitment of people with ID (Frey, Buchanan, & Sandt, 2005). In the event that participants could consent for themselves, participant consent forms were given to those individuals. In the event that participants could not give their own consent, assent was obtained instead, and a substitute decision-maker was identified to provide consent on their behalf (see Appendix H).

Participants were included based on the following inclusion/exclusion criteria: (a) attended one of the two programs, (b) was between the ages of 18 and 65, (c) was English-speaking, (d) was able to use verbal communication that is sufficient for contributing to a focus group interview, and (e) was able to provide voluntary informed consent or assent (see Appendices F and G). Ethics approval for this study was obtained

by the Research Ethics Board at the University of Ontario Institute of Technology. Participants each received a \$10 gift card to Tim Horton's as an honourarium for participating.

### **3.3.3 Data Collection**

Focus groups were selected as the method of data collection because they effectively gather information of multiple participants concurrently and have been shown to be effective in research with adults with ID (Bowers et al., 2016). One of their benefits is their semi-structured and open nature, which allows for a free, spontaneous, and more natural discussion (Kaehne & O'Connell, 2010). Abbott and McConkey (2006) explain that the effectiveness of the focus group method lies in its ability to facilitate discussion by offering "opportunities of peer support and validation of common experiences" (p.278). According to Kaehne and O'Connell (2010), focus groups are especially suitable for a population that is highly heterogenous, generally poorly understood, and who experience disparities in their health and well-being. This form of data collection is inclusive, patient, and appears to be the most appropriate technique in research that examines the facilitators and barriers to health-promoting activities in this population.

Identifying suitable locations for conducting the two focus groups was based on preference of the participants and convenience for all parties; for this reason, both groups were interviewed at their respective programs in quiet, private rooms. The interviews lasted between 70 and 80 minutes, until the point when all interview questions had been asked and relevant topics had been exhausted.

Discussion was guided by semi-structured interview questions (see Table 1 or Appendix K), which were developed based on previous literature and the principal investigator's personal insights. The interview questions were piloted first by the supervisory committee, then by three young adults with ID with whom the principal investigator was familiar. In light of any power imbalances that may exist between the principal investigator and participants of a vulnerable population, the principal investigator asked questions in a direct, concrete, and unbiased way. Any personal opinions held by the principal investigator were respectfully withheld (Creswell & Poth, 2018). The focus group discussions were audio-recorded and then stored as audio files. The principal investigator transcribed the focus group audio recordings verbatim before proceeding to data analysis.

A demographic survey was also used to collect information about participants that would help to describe the sample. The survey collected information about participant age, gender, residential type, residential location, and their estimation of the frequency of their physical activity (see Appendix I).

Table 1. Interview Guide Questions

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Interview Guide	
1)	I want to know more about you. Tell me about some of your favourite activities and hobbies. <ul style="list-style-type: none"><li>• <i>Probe:</i> free time, during the day</li></ul>
2)	(a) Raise your hand if you like to play sports sometimes? (b) <u>Why</u> do you like to play sports?
3)	(a) Raise your hand if you like to exercise/work out sometimes? (b) <u>Why</u> do you like to exercise/work out?
4)	<u>What</u> or <u>who</u> helps you stay active? <ul style="list-style-type: none"><li>• <i>Probe:</i> Is there something that gets you moving or gets you motivated? How do they help you? Who <u>could</u> help you stay active/what about other people?</li></ul>
5)	<u>Where</u> do you go to play sports or exercise? <ul style="list-style-type: none"><li>• <i>Probe:</i> Do you have a favourite place you go to play sports/be active/exercise?</li></ul>
6)	<u>How</u> do you get to those places? <ul style="list-style-type: none"><li>• <i>Probe:</i> What form of transportation do you take to get there?</li></ul>
7)	What happens when no one can take you to those places? <ul style="list-style-type: none"><li>• <i>Probe:</i> if you don't have someone to take you, do you still go? How do you get there?</li></ul>
8)	What makes it <u>hard</u> for you to stay active? <ul style="list-style-type: none"><li>• <i>Probe:</i> is there something that stops you from being active? On days that you are not doing sports or working out, why not?</li></ul>
9)	(a) Raise your hand if you don't like to play sports sometimes? (b) <u>Why</u> don't you like playing sports?
10)	(a) Raise your hand if you don't like to exercise sometimes? (b) <u>Why</u> don't you like exercising?
11)	[Some of you already told me about some programs that you attend.] <u>Why</u> do you go to those programs? <ul style="list-style-type: none"><li>• <i>Probe:</i> What is good about it/What do you like about it?</li></ul>
12)	Last question: Are there physical activities/sports/exercises that you used to do, but stopped doing? <ul style="list-style-type: none"><li>• <i>Probe:</i> Why did you stop? What about when you were a kid or teenager?</li></ul>

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### 3.3.4 Data Analysis

Following each focus group, audio recordings were saved as an audio file on a secure server. After the completion of verbatim transcribing, the transcripts were read multiple times by the principal investigator in order to develop familiarity with the data. Following this process, the principal investigator looked for recurring words and patterns, referred to as ‘codes’ (Creswell & Poth, 2018). The process of coding was completed using NVivo 12 qualitative analysis software to identify codes and sort them into higher-level categories and broader themes. Saldaña (2013) states that coding is an iterative, “cyclical act” (p.8) that becomes more fine-tuned the more a researcher immerses oneself in, and interacts with, the data. For this study, multiple rounds of coding took place in order to sort through the meaning of the data and gain a clearer picture of the codes, categories, and broader themes.

In the early stages of coding, referred to by Saldaña (2013) as ‘First Cycle’ coding, the principal investigator analyzed the data, generating preliminary codes. Then, following a consultation with the research team to minimize bias and improve code phrasing, a codebook was created and finalized. In the latter stages of coding, referred to as ‘Second Cycle coding’, the principal investigator worked to sort lower level codes into larger categories, and those categories into even broader, more representative themes (Saldaña, 2013). ‘Themes’ are the more comprehensive, tangible concepts that are derived from the various, more narrow topics discussed by participants (i.e. codes) (Creswell & Poth, 2018). Once coding and theming were completed, a second coder coded 20 percent of the transcripts by applying the codes from the codebook; this is referred to as *inter-rater reliability* testing (Creswell & Poth, 2018). A statistical test was

run in the NVivo program that compared the two coders' coded text portions, and returned an inter-rater reliability Kappa score of over 99%. This established that there was a very high level of agreement between coders, so thematic analysis could continue to be refined and finalized. The principal investigator then completed the categories and themes.

In addition to thematic analysis, the principal investigator also conducted code counting (counting the number of times codes appear in the data) (Elliott, 2018; Saldaña, 2013). According to Elliott (2018), counting codes is a pragmatic and systematic approach to qualitative research that can provide indicators to the importance of codes. However, as Saldaña (2013) states, "Frequency of occurrence is not necessarily an indicator of significance" (p. 39). Rather than give precedence to frequency of code appearance, counting codes was performed only to contextualize the themes and call attention to meaningful patterns in the data.

In this study, the themes materialized as *types of facilitators and barriers* experienced and perceived by the participants. Pertinent participant quotes were then drawn from the transcripts and used to illustrate themes and act as contextual examples. As recommended by Creswell and Poth (2018) and Saldaña (2013), a reflective journal and analytic memos were maintained from the beginning to the end of data analysis in order to log researcher thoughts and decisions.

### **3.4 Results**

#### **3.4.1 Demographic Information**

Participant demographic information is described in Table 2, below. All participants were adults with ID. There were nine females and four males (n=13). The

age range was 21 to 42 years, (mean: 28, median: 26). There were two participants whose ages were not reported, so their age data could not be included in the sample description. The first group consisted of 10 participants. Eight participants verbally contributed to the discussion, and two participants spoke very little or not at all. The second group consisted of three participants, all of whom verbally contributed to the discussion.

Of the 13 total participants, 10 resided within the Durham Region (the region east of the city of Toronto) and three participants resided in the York Region (the region north of the city of Toronto). The majority of participants (n=10) reported themselves to be active ‘a few times a week’ or ‘once a week’, while two participants reported themselves to be active ‘every day’, and one participant reported herself to be active ‘rarely/almost never’. Most participants lived with their parents in a house and were unemployed.

Table 2. Participant Demographic Information

Participant	Sex	Age	Type of residence	Living situation	Employed
1	male	28	House	With parents	No
2	female	26	Condo	With parents	Yes
3	male	25	House	With roommates + support staff	No
4	female	42	House	With parents	No
5	female	23	House	With parents	No
6	female	21	House	With parents	Yes
7	female	32	House	With parents	Yes (“volunteer”)
8	female	37	House	With roommates + support staff	No
9	male	not stated	House	With parents	No
10	male	22	House	With parents	No
11	female	not stated	House	With parents	No
12	female	25	House	With parents	No
13	female	27	Apartment	With parents	No

*Note.* In the demographic survey under “Do you have a job?”, Participant 7 indicated instead that they volunteer.

### 3.4.2 Code Frequency Analysis (‘Code Counting’)

The procedure of counting codes helped to represent: (1) the most-discussed topics, and (2) the overall participant perspectives of facilitators versus barriers. This type of analysis added another layer to the results by presenting the amount of attention that participants accorded to certain topics.

**References to Facilitators versus Barriers.** Table 3, below, contains the number of times that facilitators and barriers were respectively brought up by participants. This information demonstrates that participants identified and discussed facilitators at more than twice the frequency than they identified and discussed barriers.

Table 3. Number of References to Facilitators and Barriers

Type of theme	Number of references
Facilitators	204
Barriers	98

**References to Various Topics (Which Emerged as Themes).** Table 4, below, presents a breakdown of themes that were most frequently talked about by participants. The number of references made to each theme demonstrates the amount of attention that was paid to it.

Table 4. Number of References to Themes

Theme (facilitators or barriers)	Number of references in transcripts
Support (facilitators)	77
Internal (barriers)	62
Individual (facilitators)	60
Resources (facilitators)	42
Programs (facilitators)	39
Not Recognizing or Understanding Barriers (barriers)	26
External (barriers)	23

*Note.* Themes are the over-arching categories that encapsulate the smaller, more specific topics of discussion (codes) brought up by participants. Themes fell under the category of ‘facilitator’ or ‘barrier’, and these identifiers appear in parentheses beside each theme. Themes appear in the order of most- to least-frequently reported.

**References to Activity Types.** Table 5, below, presents a breakdown of the number of references made to certain types of activities brought up by participants. The number of references made to each activity type demonstrates the amount of participant attention that was paid to each topic.

Table 5. Number of References to Activity Types

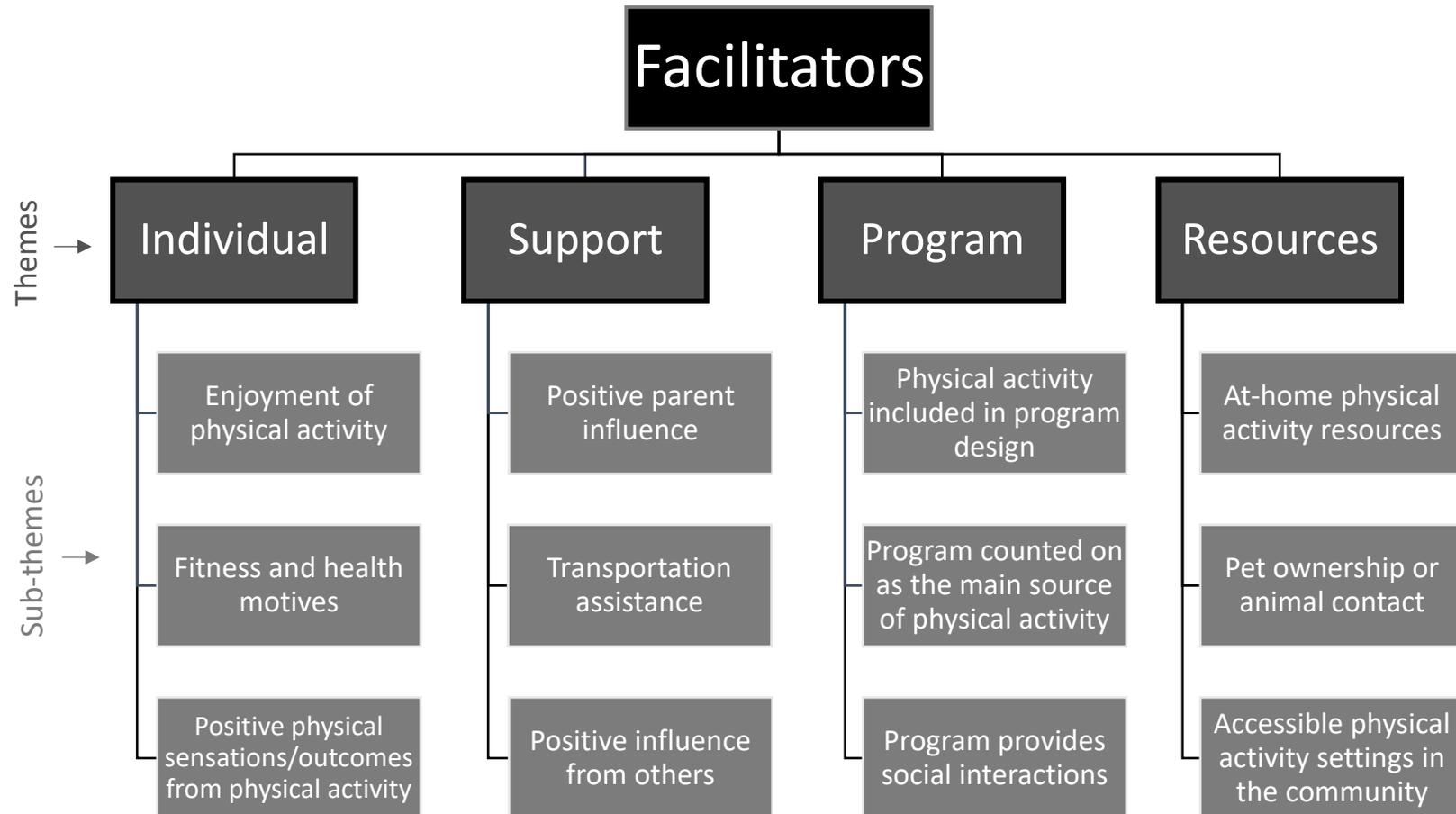
Activity type	Description and example	Number of references in transcripts
Leisurely (non-structured)	Refers to a type of light physical activity that is done during one's free time, for the main purpose of enjoyment. (e.g. playing pool with friends)	52
Program-based (structured)	Refers to a type of physical activity that is done as part of an organized, structured, and sometimes team- or group-based program. (e.g. daily exercise routine at day program)	43
Sedentary (non-structured)	Refers to a type of activity that is very low in bodily movement and intensity (e.g. colouring, watching television)	38
Moderate-to-Vigorous (non-structured)	Refers to a type of physical activity that is done for the purpose of sustaining or improving fitness and health. (e.g. mini-trampoline workout)	24

*Note.* Activity types are mutually exclusive, meaning activities mentioned by participants were coded into only one category (i.e. activities that were described by participants as happening at programs cannot also be categorized under moderate-to-vigorous; the activity was categorized into the most-appropriate activity type). The examples of each activity type are pulled from actual participant descriptions in this study. Activity types appear in order of most- to -least-frequently reported.

### 3.4.3 Thematic Analysis of Facilitators and Barriers

Qualitative thematic analysis was the primary focus of this study; thematic analysis of the focus group data generated meaningful insight into participants' experiences with physical activity. Participants spoke about numerous topics in response to the interview guide questions, and these ultimately emerged as the answers to this study's research question: *What are the facilitators and barriers to physical activity experienced and perceived by adults with intellectual disabilities?* Figure 2, below, depicts the diagram of *Facilitators* and Figure 3 depicts the diagram of *Barriers*. The two diagrams present the 'essence' of the data as organized into broad themes, and their respective sub-themes.

Figure 2. Facilitators to Physical Activity: Themes and Sub-themes



**Reported Facilitators to Physical Activity.** Several facilitators to physical activity emerged from the focus groups. Facilitators were any people, resources, locations, or functions that participants expressed as helping them be physically active. Facilitators can also be thought of as anything which could potentially overcome barriers (Taliaferro & Hammond, 2016). The facilitator themes and sub-themes are described in more detail below.

**Theme: *Individual facilitators.*** Participants primarily reported facilitators that fell within the context of their own influence, as opposed to the influence of others. Participants perceived many facilitators that centred around their own attitudes, motives, and feelings. The most prominent *Individual* facilitator sub-themes include: *Enjoyment of physical activity*, *Fitness and health motives*, and *Positive physical sensations/outcomes from physical activity*. Below are descriptions of each sub-theme and associated quotes taken from the transcripts that help to represent them.

**Sub-theme: *Enjoyment of physical activity.*** This *Individual* facilitator sub-theme refers to the positive feelings held by participants toward physical activity. Many participants expressed a general enjoyment of being active, but most said that they enjoyed taking part in specific physical activities.

When participants shared their favourite physical activities or were asked why they liked engaging in them, many of the participants showed enthusiasm and passion.

**Participant:** “Oh yeah, and I like dancing and singing. That's the best part of all.”

Interviewer: “Why do you do swimming lessons?”

**Participant:** “Because swimming lessons... because umm, it's my most favourite thing.”

Interviewer: “Why do you play sports?”

**Participant:** “Just for fun.”

*Sub-theme: Fitness and health motives.* This *Individual* facilitator sub-theme relates to the physical and physiological reasons that participants had for being active and getting fit.

Most participants described goal-oriented motives for being active.

Interviewer: “Why do you like to exercise?”

**Participant:** “To stay fit and to get my muscles bigger in my arm.”

**Participant:** “I'm trying to get a six pack. Eight pack.”

Some participants explained that there was a preventative reason for being active.

Interviewer: “Is there anything else you can think of about why you exercise?”

**Participant:** “You don't get like, type one diabetes.”

Interviewer: “Oh, so back to the health thing. Yeah. It's important to prevent it.”

**Participant:** “Yeah, because my, my grandfather had it.”

*Sub-theme: Positive physical sensations/outcomes from physical activity.* This *Individual* facilitator sub-theme emerged from participants expressing positive bodily outcomes from participating in physical activity. This facilitator closely relates to the first sub-theme, *Enjoyment of physical activity*, because it appears to

enhance enjoyment and may therefore evoke feelings of wanting to continue to participate in the physical activity in which they feel good while participating in.

Interviewer: “Why do you exercise?”

**Participant:** “Just makes me feel good. Makes me feel a lot better.”

**Participant:** “I used to not like going to the gym but I like it more because I'm stronger than I used to be.”

**Theme: Support facilitators.** Participants frequently discussed the sources from whom they receive support to help them participate in physical activities. Parents appeared to be the most impactful source of support, specifically in the forms of encouragement and participation. Overall, *Positive parental support* was the most salient *Support* facilitator. *Transportation assistance* was another *Support* facilitator sub-theme that was an enduring point of discussion. *Positive influence from others*, such as friends, siblings, coaches, and staff were also identified as playing important facilitating roles.

**Sub-theme: Positive parent influence.** As evidenced by the number of times parents were discussed, this source of support had by far the most impact on participants' lives. Almost all participants who reported living with their parents described multiple ways in which their parents help them succeed in being active. Participants who reported not living with their parents did not mention their parents as much or at all. Instead, those who lived in a group home reported that their support staff sometimes helped them stay active. Encouragement, being

involved, role modelling, and authority were all ways in which participants reported that their parents helped them be active.

Most parental support came in the form of encouragement and guidance.

**Participant:** “I always go swimming and the treadmill with my mom.”

Interviewer: “Cool. She treadmills with you?”

**Participant:** “Umm, my mom helps me how to use the treadmill.”

Some participants reported their parents as being more commanding in ensuring they were engaging in physical activity.

Interviewer: “You exercise too?”

**Participant:** “Umm sometimes I do but I don't like it that much.”

Interviewer: “You don't like it that much?”

**Participant:** “No, because my mom told me to - I have to, and I listen to my mom.”

Some participants reported that their parent(s)' involvement in a sport or exercise was a reason for them participating in it.

**Participant:** “My mom's actually a coach for baseball.”

*Sub-theme. Transportation assistance.* Overall, it appeared the large majority of participants mostly depend on their parents for transportation, and rely on parental assistance when using accessibility transit buses or taxis.

The topic of transportation was discussed by many participants, most of whom reported being driven by their parents to places of physical activity.

Interviewer: “So how do you get to swimming?”

**Participant:** “In a car.”

Interviewer: “In a car, okay.”

**Participant:** “With my mom or my dad.”

Interviewer: “While you were on the waitlist, when you were waiting to take the (accessibility transit) bus, how did you get here?”

**Participant:** “Well, my step-dad – my step-dad, like, takes me there and picks me up after. Mostly my mom picks me – mostly my mom takes me there, and drop me off after. And she picks me up after.”

Some participants stated that they sometimes take accessibility transit buses or taxis, and that their parents assisted them in the process.

**Participant:** “My mom usually will phone up the bus company to let me – to let them know, to let them know, if I don't need a ride or not.”

*Sub-theme: Positive influence from others.* This *Support* facilitator sub-theme encompasses the references to sources of support and assistance from non-parent individuals. Non-parent family members and friends were reported as sources of encouragement and assistance. Program staff and volunteers, coaches, and trainers were also identified as playing a facilitating role in staying active.

Interviewer: “Are you good at (pool)?”

**Participant:** “Yeah, I started playing pool. All my friends - all my friends at (another program) plays pool. My staff plays pool too, and my boyfriend plays pool, so I started following the footsteps.”

**Participant:** “My trainer helps me too. At the gym, when I'm working out with her, she reminds me.”

**Theme: Program facilitators.** Participants spoke positively about the variety of activities they do at the programs they attend. When asked about the physical activities they participate in, the answer most frequently related to programs. There appeared to be an abundance of physical activity and other opportunities

offered by programs that the participants enjoyed taking advantage of. The *Program* facilitator sub-themes include: *Physical activity included in program design*, *Program counted on as the main source of physical activity*, and *Program provides social interactions*. Below are participant quotes as evidence of these sub-themes.

*Sub-theme: Physical activity included in program design.* Participants often mentioned physical activities that their program offered them. Both of the programs from which participants were recruited offered some sort of sport and/or exercise opportunities and the participants appeared eager to discuss them.

**Participant:** “I got to join a program in Newmarket and they play basketball in the afternoon.”

**Participant:** “Every Monday we have a (dance) class.”

Interviewer: “Where does that happen?”

**Participant:** “It's in the field house.”

Interviewer: “Oh, it happens here (at the day program)?”

**Participant:** “Yeah.”

Interviewer: “*During* (the day program)?”

**Participant:** “Yeah.”

*Sub-theme: Program counted on as the main source of physical activity.* This *Program* facilitator sub-theme emerged because many participants brought up the day programs when they were asked about the types of physical activities that they participate in. They expressed how they were physically active primarily at their day programs. This serves to demonstrate the importance of having access to day programs that offer physical activity opportunities for adults with ID.

One participant had not been attending the day program for long and she was looking forward to continue attending throughout the seasons.

Interviewer: "What do you do in the winter?"

**Participant:** "Winter? I mostly hope I come here. The winter session."

Interviewer: "Oh, you do a winter (session) as well?"

**Participant:** "Yep."

There was one participant who expressed her appreciation of the exercise facilities available to her at the day program, which are not available at her home.

**Participant:** "We're supposed to get a gym for the house, but the - but my house is way, way too small."

Interviewer: "Hm, so you would work out at home, but you don't have a home gym?"

**Participant:** "It's *here*, that I got the *whole gym!*"

*Sub-theme: Program provides social interactions.* Another prominent point of discussion was the opportunity to see friends and meet new people at their day programs. It became clear that, although the interviewer was prompting participants to discuss physical activity, many of them desired to discuss the of importance of the social aspect of programs.

Interviewer: "Is there anything else that, like, makes you want to keep going back to baseball or other sports?"

**Participant:** "Well, it gets me, gets me to know new people and more new players."

**Participant:** "Yeah they (my friends at the program) are like family to me."

**Theme: Resources facilitators.** Participants made mention of some tangible resources that help them stay active. The *Resources* facilitator sub-themes include: *At-home or neighbourhood physical activity resources*, *Pet ownership or animal contact*, and *Accessible physical activity settings in the community*.

**Sub-theme: At-home physical activity resources.** This *Resources* facilitator sub-theme was shown to be quite important for participants, as many described in-home equipment (e.g. weights), outdoor equipment (e.g. bicycles), and their home's immediate built environment (e.g. sidewalks). The following quotes provide some evidence of accessible, at-home resources that participants make use of.

**Participant:** "I always do like playing basketball on my basketball court outside. And I always ride my bike. It's fun. And sometimes I always do my weights. I have weights at home."

**Participant:** "I exercise with my mom in the exercising room in my condo. And I go to water aerobics with my mom in the swimming pool downstairs."

**Participant:** "And I sometimes go for walks."

Interviewer: "Hm, and where do you go for walks?"

**Participant:** "Around the block."

**Sub-theme: Pet ownership or animal contact.** Pets and animals were a less-talked-about topic, but multiple participants did describe the positive influence of pets and animals in their lives. Dogs, especially, were mentioned on multiple occasions due their inherent need to be walked outdoors.

Interviewer: "Would you say your dog helps you stay active?"

**Participant:** “Sometimes.”

Interviewer: “Sometimes. Okay.”

**Participant:** “I play with her, with toys, to play with her sometimes.”

**Participant:** “I always take my bike go to a beach... And see like wild animals. Sometimes so like, animals come over, then I give them – feed them a lot of bread.

A participant described his access to farm animals at a program he attends, which he described as a facilitating factor to being active in different ways.

**Participant:** “(At the program) I always do like, with everybody, we always do go outside, go see petting with the animals. And hay rides; I always do that. Sometimes we do like, we go walk down to the stables and do some grooming with horses.”

*Sub-theme: Accessible physical activity settings in the community.* Accessible physical activity settings and facilities act as an extension of resources available at home. Few participants reported having a gym membership, and so appeared to rely on programs for physical activity opportunities. For those who *did* express having access to local settings or facilities, they spoke positively about them.

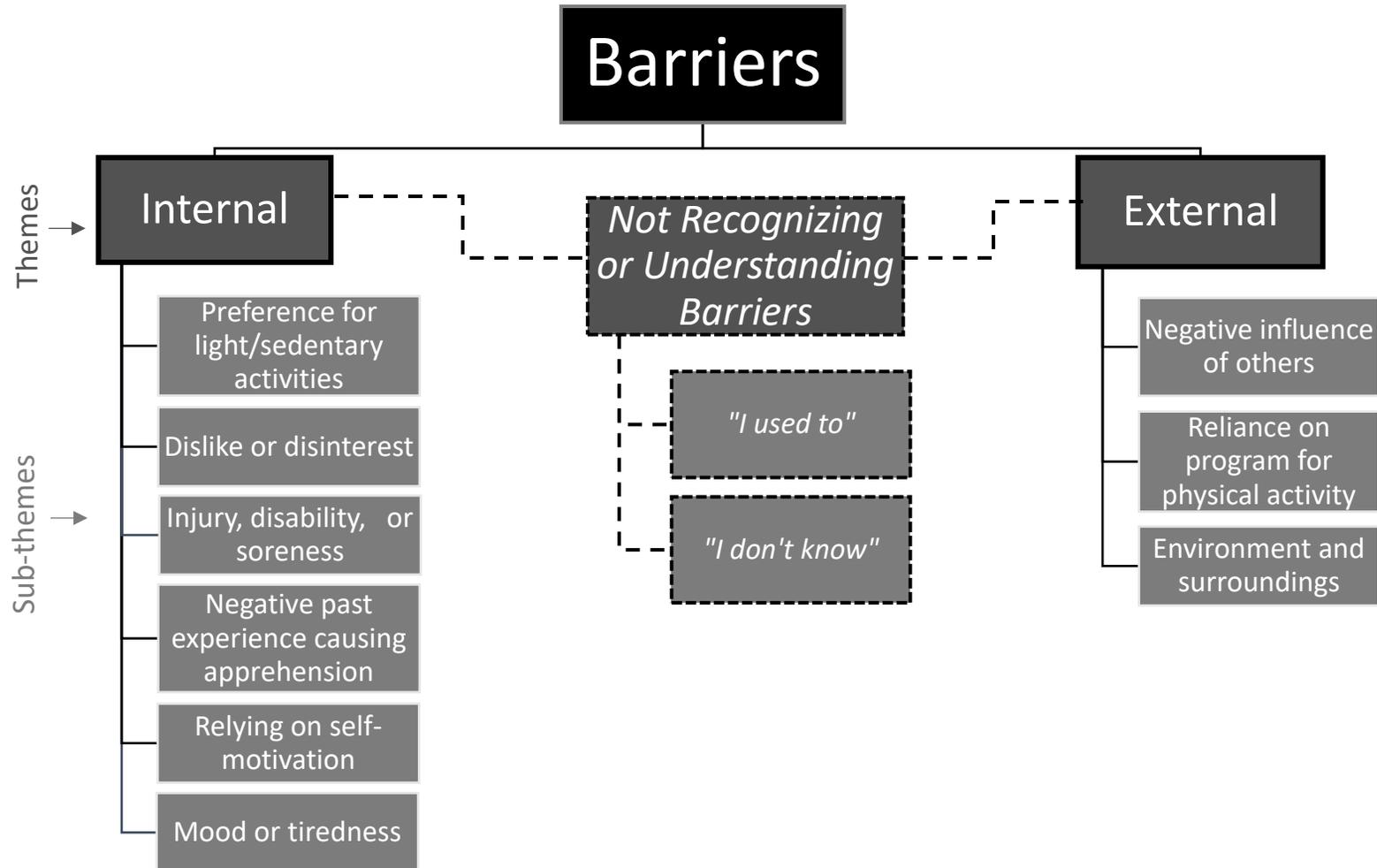
**Participant:** “I like to go swimming at the gym.”

Interviewer: “The gym? Your gym has a pool?”

**Participant:** “Yeah.”

**Participant:** “I go to (the community centre). Sometimes I ride my bike up there.”

Figure 3. Barriers to Physical Activity: Themes and Sub-themes



**Reported Barriers to Physical Activity.** Barriers to physical activity can be understood as any factor that slows, complicates, or prevents a person's ability to be active (Cambridge English Dictionary, n.d.) and are factors that must be overcome in order to increase or enhance physical activity (Taliaferro & Hammond, 2016). The barrier themes and sub-themes are described in more detail below.

*Theme: Internal barriers.* Participants primarily reported barriers that fell within the context of their *own* influence, as opposed to the influence of others. This is reflected by the number of sub-themes that fell under the *Internal* barriers theme compared to the number of sub-themes that fell under the *External* barriers theme. Many participants reported that their preferences and attitudes toward physical activity, as well as physical injuries and feelings, were influences of their participation. *Internal* barrier sub-themes include: *Preference for light/sedentary activities, Dislike or disinterest, Injury/ disability/ soreness, Negative past experience causing apprehension, Relying on self-motivation, and Mood or tiredness.*

*Sub-theme: Preference for light and sedentary activities.* This *Internal* barrier sub-theme was constructed as a representation of how often participants discussed sedentary or more-passive activities in a focus group aimed at discussing physical activities. Many reported that their favourite hobbies were such things as colouring, watching television, and talking on the phone. Even when prompted to discuss physical activity, many chose to discuss less-active leisure-time pursuits. Below are participant quotes that help to provide evidence of this sub-theme's hindering influence.

**Participant:** “But sometimes it's lazy sometimes. Because I love (writing) stories the best.”

Interviewer: “So you prefer to (write) stories instead of exercise?”

**Participant:** “Well, sometimes I do both. Sometimes I do. Sometimes I don't.”

**Participant:** “I like to play video games. And listen to music, or watch TV with mom and her boyfriend. And I also like to go out with them... We usually go to play euchre, when it's euchre night.”

*Sub-theme: Dislike or disinterest.* This *Internal* barrier sub-theme refers to participants' negative personal attitudes or feelings about participating in physical activity. Although this sub-theme relates closely to the above sub-theme, *Preference for light or sedentary activities*, it is distinct in that many participants were not necessarily averse to being active as a whole, but were disinterested in some *specific* types of physical activities. The following quotes illustrate how some participants disliked some forms of physical activity.

**Participant:** “I used to play basketball, baseball, basketball again, baseball. I stopped because I did not like it.”

Interviewer: “Oh okay. So, you didn't like basketball or baseball?”

**Participant:** “No, I'm not into sports.”

**Participant:** “Well I don't like jumping rope anyway. And, um, some race anyways. I don't like race that much. (Those are things that get) in my way (of being active).”

Interviewer: “So, it sounds like the biggest thing for you to not exercise is that you just don't like it. Is that true?”

**Participant:** “Uhh, yeah. I don't like - I don't like doing that stuff because I love junk food a lot. I love chocolates.”

*Sub-theme: Injury, disability, or soreness.* This *Internal* barrier sub-theme refers to references that participants made to having a physical injury, a physical disability, or a feeling of soreness which had a negative impact on their ability to participate in physical activity. Only a few participants reported this barrier, but those that did expressed it multiple times and it was apparent that it was a strong hindrance to their physical activity.

Interviewer: “Why don't you (play sports) anymore?”

**Participant:** “My knee.”

Interviewer: “You injured it?”

**Participant:** “No, I just got bad arthritis in it. So my left it just aches.”

Interviewer: “Oh no.”

**Participant:** “Twice as bad when it's cold. That's the only reason why I stopped.”

**Participant:** “I get tired quickly. And sore. And sometimes my back is sore too.”

*Sub-theme: Negative past experience causing apprehension.* A number of participants described physical activity experiences as something that was distressing to them, specifically relating to physical pain or discomfort. This topic was brought up by five different participants across the two focus groups, and the similarities between experiences were striking. These participants expressed a fear, unwillingness, or disinterest to return to a physical activity because of their experience; this is illustrated in the participant quotes below.

**Participant:** “I like bocce ball and floor hockey but I don't like soccer. I don't wanna get hit in the face. 'Cause I was goalie so that's why.”

**Participant:** “Umm, (I feel) nervous if I get hit with the balls. I usually - I always get hit with the balls.”

Interviewer: “You do? A lot?”

**Participant:** [nods head 'yes']

Interviewer: “Oh... Does that make you want to stop playing?”

**Participant:** “Yes. Getting smacked with the balls.”

*Sub-theme: Relying on self-motivation.* This *Internal* barrier sub-theme describes the phenomenon of some participants in this study expressing a desire to initiate their own physical activity, but would realistically fail to do so if not for external influence. The barrier of reliance on self-motivation is demonstrated by dialogue between the interviewer and participants below.

Interviewer: “Is there someone who helps you exercise or play sports?”

**Participant:** “Actually I decided myself.”

Interviewer: “Okay. So, you decide to...”

**Participant:** “Yeah I just wanna do it by myself anyways. Not my mom or my dad either because, umm, it's so hard to do it - my body - I don't like exercise that much. It's too hard work.”

Interviewer: “Is (choosing your activities) something that you like to do by yourself?”

**Participant:** “Yes, but (my parents) don't understand that.”

Interviewer: “If they didn't remind you, would you be active?”

**Participant:** “No.”

*Sub-theme: Mood or tiredness.* Some participants made mention of a negative temporary emotional feeling, such as a bad mood or tiredness, having an impact on their desire to participate in physical activity. This is illustrated by the quotes below.

**Participant:** “Sometimes, if I have umm a long day and I'm tired and I don't wanna do anything.”

**Participant:** “If I have a hard day then I don't go (to the gym).”

Interviewer: “Okay. What do you mean by that?”

**Participant:** “Like, if I was upset during the day I usually don't go.”

**Theme: External barriers.** Participants expressed some negative external influences which emerged as three sub-themes: *Negative influence of others*, the *Reliance on program for physical activity*, and *Environment and surroundings*. Below are the *External* barrier sub-themes and associated participant quotes that help to explain them.

**Sub-theme: Negative influence of others.** Participants expressed that their physical activity often occurred due to the encouragement, assistance, or supervision of someone else, and when that form of support diminishes, so does their participation.

There was one participant who had stopped bowling because of her parent's injury.

Interviewer: “And, why did you stop (bowling)?”

**Participant:** “Because of my mom's wrist. In her wrist, she has carpal tunnel in her wrist.”

Another participant's physical activity was negatively impacted by the cessation of his instructor.

**Participant:** “I did some like karate a long time ago but I not do that anymore because my sensei, I got two of them, one of them - one of them not doing it this year. They don't want to do it 'cause they got new thing they like to do.”

One participant ended his participation in a sport due to friends no longer being able to attend.

**Participant:** “We used to play baseball. I'm not doing that anymore 'cause my friends are not there anymore. They moved. And one best friend I have is - he lives in - he moved to Oshawa, not in Ajax anymore, in Pickering.”

*Sub-theme: Reliance on program for physical activity.* This *External* barrier sub-theme describes the over-reliance on programs as a place to be active. A number of participants described that their day program(s) were the main, or sometimes *only*, place where they participated in physical activity.

Interviewer: “Are you in swimming or no?”

**Participant:** “No. I'm not here on Fridays...”

Interviewer: “So, you miss out on it?”

**Participant:** “Yeah. It would be good for my muscles though.”

**Participant:** “And (I'd choose to) be here (at the day program) all day.”

Interviewer: “But you do do exercise here, right?”

**Participant:** “Yeah.”

Interviewer: “And you're— you like that?”

**Participant:** “Yep.”

Interviewer: “But at home you don't like to be reminded to exercise?”

**Participant:** “No! No.”

*Sub-theme: Environment and surroundings.* This *External* barrier sub-theme includes both natural and built surrounding structures, as well as the weather and climate. These were identified by participants as barriers to being active, and examples from the transcripts are below.

**Participant:** “I live in an apartment building so it's kind of hard for me to walk around my apartment.”

**Participant:** “Sometimes easy, sometimes hard. And the hard part is actually is like weather. Like on rainy days or snow days. Don't go out there like thunderstorms... That's a bit hard, like if you have snow storm. It's hard to go out there 'cause it's dangerous, has like ice on there and you don't wanna trip and fall, or uhh, like that. That's why that's the hard part, like when seasons change.”

**Theme: *Not recognizing or understanding barriers.*** Participants often elected to discuss past physical activities instead of current ones when responding to questions (referred to as the “*I used to*” barrier sub-theme). Participants also appeared to lack knowledge about why they stopped certain physical activities (referred to as the “*I don't know*” barrier sub-theme). Descriptions and participant quotes are included below.

**Sub-theme: “*I used to*”.** Participants spoke prominently about previous physical activity. When they were prompted by the interviewer to discuss current physical activities, some participants kept reverting back to descriptions of childhood and adolescent school-time sports, teams, and classes, or adulthood physical activities that they had ended their participation in. Evidence of this sub-theme can be seen in participant quotes below. Note that most of the interviewer’s questions prompted participants to discuss physical activity in the *present-tense*, not what they had participated in in the past.

Interviewer: “Do you have anything to add, about why you like sports?”

**Participant:** “I like sports because like, keeps me active and I done it in high school.”

Interviewer: “Alright. Do you do - do you a lot of the sports that you did in school now?”

**Participant:** “Uh, I used to.”

Interviewer: “Is there somewhere else you go to play sports?”

**Participant:** “I used to play baseball, basketball, and bowling. I used to be in a bowling league.”

**Participant:** “Um, I used to play baseball when I was young but I don't anymore. And then, um, in my class, we - we always just - we did Special Olympic stuff. And I used to - we used to do, umm, well before I graduated, we used to do umm, bocce ball, soccer and floor hockey. I did all three.”

*Sub-theme: “I don't know”.* Participants discussed barriers to physical activity less than half as frequently as they discussed facilitators (refer to Table 3). Some participants stated that they did not know why they ended their participation in a physical activity, and some participants decisively expressed that they perceive few or no barriers at all. Below are participant quotes that help to highlight the phenomenon of seeming to not recognize barriers that stand in their way of being active.

Interviewer: “Anything else that makes it kind of challenging to exercise?”

**Participant:** “No, not really no.”

Interviewer: “You find it pretty easy to stay active?”

**Participant:** “Of course.”

Interviewer: “Okay. Why did you stop (doing the bowling league)?”

**Participant:** “Um, I'm not sure the reason why I stopped. I'm not sure.”

Interviewer: “You don't know why you stopped?”

**Participant:** “No.”

A particularly interesting instance of a participant not fully understanding the barriers to her physical activity was when she demonstrated that did not know the exact reason why she is not participating in a sport she is interested in, horseback riding. She seemed to rely on the suggestions of others for possible explanations without desiring to, or knowing how to, identify the true barrier(s).

(The participant expressed a desire to do horseback riding, saying that the barrier was:) “I don't have a horse.”

(When it was clarified that she could horseback ride without having to own one, she said the barrier was:) “My mom won't let me do it.”

(When asked to explain why, she stated:) “I don't know why but ask my mom, I don't know.”

(At this point, another participant who *does* horseback ride interjected, speculating that it might be because it is too expensive to ride, leading to the original participant changing her answer about the barrier to:) “It's too expensive.”

### 3.5 Discussion

Physical activity is important for maintaining fitness and health (Warburton et al., 2010); however, the evidence indicates that adults with ID struggle to be active at a satisfactory frequency and intensity, even more so than adults with TD (Dairo et al., 2016). This has led researchers to investigate the reasons behind this trend. The aim of the present study was to expand upon previous research by exploring the facilitators and barriers to physical activity experienced and perceived by adults with ID. Results from focus groups with 13 participants indicate that a large variety and number of factors act to influence their physical activity, in both facilitating and hindering ways. In total, seven overarching themes emerged from the data: four facilitator themes (*Individual, Support, Program, Resources*) and three barrier themes (*Internal, External, Not Recognizing or*

*Understanding Barriers*). This discussion consists of an overview of the types of physical activities in which participants are involved, followed by a reflection on facilitators and barriers as a whole, and then a discussion of the key influences of their physical activity: individual enjoyment, preference and disinterest, fitness and health, parents, programs and social opportunities, and unrealized barriers. These findings are discussed within the context of the current body of literature.

### **3.5.1 An Overview of Reported Physical Activities**

Participants in this study described a wide variety of physical and non-physical activities that they currently and previously participated in. Although definitive conclusions cannot be drawn about the types of activities participants actually participate in based on how often they discussed them, knowing how often they referred to activities can still help to contextualize their reports and provide a larger picture of their experiences with, and perspectives of, their own physical activity. To gain a clearer understanding of their physical activities, they were categorized into four types: *Leisurely (non-structured)*, *Program-based (structured)*, *Sedentary (non-structured)*, and *Moderate-to-Vigorous (non-structured)*, all of which are mutually exclusive. In counting the number of references to each activity type (see Table 5), it was interesting to see the differences between categories. For instance, leisurely physical activities were most-often discussed (52 references), while moderate-to-vigorous physical activities were least-often discussed, brought up at less than half the frequency (24 references). These findings provide an idea of the lifestyles that these participants live, revealing that, although physical activity does happen, it might not be happening at high enough intensities. This reflects current evidence, which shows that adults with ID who

participate in physical activity often do so at less-vigorous intensities (Badia, Orgaz, Verdugo, Ullán, & Martínez, 2011; Charnley, Hwang, Atkinson, & Walton, 2019).

Another point of interest was that sedentary activities (38 references) were discussed more frequently than moderate-to-vigorous physical activities (24 references), suggesting generally sedentary interests among participants. Research has consistently shown that a sedentary lifestyle is common in adults with ID, more than in their peers with TD (Havercamp & Scott, 2015; Melville et al., 2016), and although participants in the present study reported a variety of physical activities, their comparatively high number of references to sedentary pursuits might indicate that they are not being adequately active. Participants also identified numerous facilitators and barriers to those physical activities, which provided an opportunity to examine how they experience and perceive physical activity, as a generally poorly-understood and under-studied population.

### **3.5.2 A Reflection on Facilitators and Barriers**

For the adults who took part in this study, it would appear that their physical activity is influenced by both internal and external factors. This indicates that their participation in physical activity is affected not only by their own internal attitudes and abilities, but also by the external world with which they interact, including people, structures, and communities. The findings from this study are consistent with the World Health Organization's *International Classification of Functioning, Disability, and Health* (WHO-ICF) model, which stipulates that personal and health conditions, combined with environmental and contextual factors, act to influence the outcome of a person's disability (World Health Organization, 2002). The results manifesting as both internal and external

influences suggest that adults with ID themselves, *and* the external world, both play roles in their physical activity participation. Therefore, the information around facilitators and barriers that emerged from this study can be utilized to make improvements to the physical activity of this population through better-informed interventions, caregiving, programs, and policy.

### **3.5.3 The Influence of Enjoyment, Preference, and Disinterest**

**Facilitators.** Enjoyment was one of the more dominant sub-themes in this study, which was not unexpected, as it has emerged in past research as one of the primary determinants of physical activity participation for this population (Messent, Cooke, & Long, 2000; Temple, 2007; van Schijndel-Speet et al., 2014). When participants in the present study were asked to explain why they liked to participate in physical activity, participants frequently used phrases such as “I like it”, “it’s my favourite”, and “just for fun”, signifying interest and enjoyment. Physical activities containing an element of fun has been reported as one of the most common facilitators among adults with ID (Bossink et al., 2017). Valuing enjoyment in physical activity pursuits is not dissimilar from adults with TD, as it has been shown to be associated with higher levels of physical activity engagement in that population as well (Salmon et al., 2003). A closely related sub-theme concerns the positive physical sensations or outcomes that participants experienced as a result of being active. Some participants explained that they are active because, “Just makes me feel good, makes me feel a lot better,” and, “It makes me feel good when I exercise.” Similarly-phrased sentiments were shared by participants in a study by Frey et al. (2005), which indicates that there may be a general ‘good feeling’ that some adults with ID associate with physical activity participation. Temple and Walkley (2007)

explain that when a reaction to physical activity is positive and rewarding, a person is more likely to continue with it. They go on to emphasize that, because adults with ID require and respond well to support and rewards, there is an amplified importance of ongoing positive support and continually rewarding experiences for this population (Temple & Walkley, 2007). Therefore, physical activity programs for this population should aim to cultivate positive physical and emotional feelings, as well as a general sense of enjoyment, in order to enhance participation.

Interestingly, even though participants were initially prompted to talk about more deliberate forms of physical activity, such as sports and exercise, some participants brought up lighter-intensity forms, such as walking for transport and ‘on-the-job’ incidental physical activity. This is a positive finding for two reasons: 1) it shows that they are active, even if at lighter intensities, and 2) it demonstrates their recognition that lighter-intensity exercise is still exercise, which indicates that walking might continue to be seen – and pursued – as an accessible, inexpensive, and well-enjoyed, health-promoting physical activity. Favourably, walking has been cited as being one of the most effective, sustainable forms of exercise for people with ID (Bartlo & Klein, 2011; Mitchell et al., 2013) and research has shown that, due to differences in energy expenditures and biomechanical efficiencies, walking may in fact be a higher-intensity exercise for some adults with ID than some with TD (Lante, Reece, & Walkley, 2010). With this knowledge, it is important that walking be encouraged and made accessible as a regular activity for adults with ID.

**Barriers.** There was an emerging theme of participants having a general preference for lighter or sedentary leisure-time activities. This was unsurprising, as a

preference for more-passive activities, coupled with disinterest and a lack of motivation, are some of the most commonly-reported barriers to physical activity in the literature for adults with ID (Bossink et al., 2017; Caton et al., 2012; Dixon-Ibarra et al., 2017; Frey et al., 2005; Mahy et al., 2010; Temple & Walkley, 2007). For instance, some participants in this study verbalized that if they did not have prompts from others, they would not make healthy decisions, such as exercising on their own or choosing nutritious foods on their own. Some also described disinterest in sports or exercise for reasons relating to difficulty, boredom, or dislike. It is important to note that preference for sedentary activities, disinterest in physical activity, and lack of motivation to be active have all been shown to have influence on physical activity participation in adults *without* ID as well, irrespective of age, sex, or ability (Pan et al., 2009; Salmon et al., 2003), so these emerging themes are not unique to adults with ID. However, internal barriers may be more pronounced in adults with ID due to the compounding effects of other barriers endemic to their disability and support needs (Caton et al., 2012). People with ID require encouragement, motivation, and positive support from others (Bergström, Elinder, & Wihlman, 2014; Brown & Brown, 2009).

There were a few participants who also described negative past experiences with physical activity, specifically being hit in the face with balls during team sports, and this seemed to be a deterrent for them, as they often went onto describe their apprehension to return to that activity again. Negative past experiences with physical activity, particularly in elimination, ball, and competitive sports, have also been reported as a barrier in past research (Frey et al., 2005). However, people with ID showing higher levels of resilience have been found to recover from negative experiences more easily, and continue

involvement in challenging activities (Goodley, 2005). Thus, fostering resiliency through ongoing social support and empowerment of the individual might reduce the feelings of apprehension or disinterest that can follow negative experiences with physical activity. Returning to the suggestion by Temple and Walkley (2007) about emphasizing positive, reinforcing experiences, there is merit in also individualizing physical activity, taking into account the person's unique preferences, interests, motivations, and abilities (Kuijken, Naaldenberg, Sanden, & Valk, 2016). Researchers have suggested that caregivers and program staff should aim to deliver physical activity opportunities that are tailored to the individual, when it is possible to do so (Bartlo & Klein, 2011; Kuijken et al., 2016; Marks, Sisirak, & Chang, 2013; Stanish & Draheim, 2007).

### **3.5.4 The Influence of Fitness and Health**

**Facilitators.** Fitness- and health-related motives were a prevalent facilitator throughout this study, which is a theme consistent with the literature (Bossink et al., 2017; Frey et al., 2005; van Schijndel-Speet et al., 2014). In a study by Frey et al. (2005), it was found that having fitness incentives or goals were facilitators to being active for adults with ID. In the present study, multiple participants shared their desires or goals to “stay fit” and “be active”, which suggests that adults with ID are aware of the fitness benefits of being active and have an internal interest and drive to attain them. One participant stated that her family history of diabetes is one reason why she exercises, explaining that her grandfather had it and that she wanted to prevent it in herself. Previous research has also identified that there are adults with ID who participate in physical activity to prevent or mitigate disease and obesity and to improve general health (Bossink et al., 2017). However, most participants in the present study reported fitness-

related benefits while very few reported health-related benefits, which suggests an area of unawareness, and may indicate a need for enhanced health and health promotion education in these participants. In a study by Hawkins and Look (2006), support staff of adults with ID believed that the most significant barrier was a lack of understanding of the health benefits of physical activity. Researchers have suggested that furthering the health knowledge of adults with ID might induce positive change in their health behaviours (Bazzano et al., 2009; Hawkins & Look, 2006; Melville et al., 2011). For instance, a seven-month-long intervention study that delivered a comprehensive health education program produced significant improvements in weight, health behaviours, and physical activity in adults with ID (Bazzano et al., 2009). To that end, physical activity interventions for this population might consider incorporating health education in order to increase sustainability, as well as disseminating health information in accessible formats (Cocks, Thomson, Thoresen, Parsons, & Rosenwax, 2018). However, because there have been conflicting findings that fail to see improvements in health behaviour following increases in health knowledge in this population (Jobling & Cuskelly, 2006), more research is required to determine the most effective ways in which health education could be provided to adults with ID (Hawkins & Look, 2006). In general, researchers recommend that the current body of health literature for the ID population is in need of more physical activity interventions, especially those that are theory-based, focus on behavioural change, and account for barriers (Marks et al., 2013; Melville et al., 2011; Stanish & Frey, 2008).

**Barriers.** The existence of physical health conditions played a hindering role for some participants in the present study, who cited physical disability-related difficulties,

back injuries, arthritis in knees, and feelings of general discomfort as interfering with their ability to participate in physical activity; this too is supported by the literature (Aherne & Coughlan, 2017; Mahy et al., 2010; Stancliffe & Anderson, 2017). It is known that adults with ID experience comparatively higher rates and an earlier onset of chronic conditions and functional limitations than the general population (Krahn et al., 2006; Marks et al., 2013). Therefore, because regular physical activity can improve, mitigate, and prevent many injuries and health conditions in adults with ID (Bartlo & Klein, 2011), there is a need to better emphasize the importance of physical activity in the lives of these adults. It has been recommended by researchers that physical activity, in addition to other health-promoting activities, needs to be emphasized and implemented to a greater degree by health care professionals and organizations that serve adults with ID, because currently, this need is not being met (Krahn et al., 2006; Marks et al., 2013).

In general, parents, support providers, and program staff and directors should use their position of support and knowledge to provide healthy options and guidance for adults with ID. All in all, enhancing fun, ensuring positive physical sensations, and promoting health knowledge as facets of physical activities can enhance the physical activity experience and potentially lead to an increased likelihood of being active (Dixon-Ibarra et al., 2017).

### **3.5.5 The Influence of Parents**

**Facilitators.** Research has shown that parents are some of most influential people in the lives of adults with ID, if not *the* most influential (Crawford, 2011). In the present study, parents appeared to be the foremost source of support identified by participants, and this is likely at least somewhat linked to the fact that most participants resided with

their parents. Unlike those with TD, it is not uncommon for individuals with ID to continue to reside with their parents into adulthood (Midjo & Aune, 2018). Since adults with ID tend to be dependent upon others for care and support, this can often mean that their activities hinge on the attitudes and actions of the people that support them (Mitchell et al., 2013; Power, 2008); in this study, parents were the primary supporters of physical activity and had clear influence over their leisure-time activities. The literature has a breadth of evidence showing that parental influence can present as both a barrier and a facilitator (Alesi & Pepi, 2017; Bossink et al., 2017; Mahy et al., 2010; Mitchell et al., 2013). For example, Mitchell et al. (2013) found that parental and caregiver involvement, encouragement, and prompts are important facilitators, but, when inadequate or negative, act as barriers. In this study, participants mainly described their parents as being facilitators to their physical activity, much more so than barriers. Parents were described as facilitators in numerous ways: engaging in casual physical activity with the participants, coaching their baseball team, guiding them on how to use gym equipment, providing prompts to exercise, and offering encouragement and motivation to be active; according to participants, these are ways in which parents can facilitate physical activity.

It is also well-documented that adults with ID are dependent on transportation assistance (Bodde & Seo, 2009; Bossink et al., 2017). The dependency on others for transport is unique to this population, as many adults with ID are never able to acquire the skills necessary to obtain a driver's licence (Clark & Scott, 2016), which is a barrier not usually experienced by adults with TD. Physical activity is influenced by this dependency because it means that adults with ID must oftentimes depend on their parent's availability to drive them, or depend on their assistance to use public

transportation. Due to this dependency, and due to the fact that transportation challenges are reported so prevalently as a barrier in this area of research (Bossink et al., 2017), it was fascinating to find that the participants in this study did not overtly perceive any transportation barriers; they reported transportation only as a facilitator. There were some participants who did mention challenges related to the accessibility transit bus (such as missing the bus and having their parents drive them instead, or having their parents call into the bus company on their behalf and experiencing frustration with the company); however, instead of transportation challenges being perceived as a barrier, participants overwhelmingly perceived parental transportation as a solution that overcame this potential barrier, likely indicating that this group of participants already experiences a high level of transportation support. Such a finding may be further evidence that support from parents is of the utmost importance to adults with ID, in both emotional and practical forms. Also, because of the density and richness of resources typical of urban and suburban geographical areas (Millward & Spinney, 2013), such as the GTA and its surrounding regions, the participants in the present study may be benefitting from well-established and interconnected disability organizations, multiple program and activity options, the well-developed roadways and transport systems, and the moderately high level of economic growth (Millward & Spinney, 2013). Adults with ID residing in rural areas likely experience different facilitators and barriers to their physical activity (Taliaferro & Hammond, 2016), and future research might consider investigating the experiences and viewpoints of adults with ID who live rurally or in areas that have fewer accessible resources, in order to confirm the influences of physical activity that are specific to those regions.

**Barriers.** While parents were mainly reported as facilitators to participants' physical activity, in some instances, parents were also identified as playing a hindering role. An example of this is when one participant reported that she no longer participated in bowling because her mom had her own injuries that prevented her from bowling herself. Another participant expressed that her parents restricted her from walking to the local convenience store, because she was "not allowed to". Related themes, such as parental decision-making and over-protectiveness, have been found in similar research (Bodde & Seo, 2009; Mahy et al., 2010; Taliaferro & Hammond, 2016). Additionally, parents' and support persons' own level of knowledge and prioritization of physical activity has been shown to affect the adults with ID for whom they care (Caton et al., 2012). In this study, participants reported that their parents placed restrictions on physical activities, such as neighbourhood walking, or chose more-passive leisure-time activities based on their own interests, suggesting that there is perhaps a lack of prioritization of physical activity in their lives. It is conceivable that parents themselves experience barriers to accessing physical activity options for their adult children. In a study by Bowers et al. (2016), parents and caregivers explained that they are often not even aware of how to enroll their adult children in appropriate physical activity programs, such as Special Olympics, and have expressed a desire for these types of programs to provide more user-friendly information and be advertised more effectively. Fortunately, based on their enrollment in the program from which they were recruited, participants in the present study have satisfactorily gained access to at least one program offering physical activity in their community. However, future research should consider examining how best to reach adults with ID and parents who might be missing out on program and

service information. Moreover, because parents and caregivers play such an essential role in the physical activity of adults with ID, it may also be worthwhile to include them in interventions aimed at increasing physical activity levels, as it can enhance accessibility and cultivate knowledge and skill development on the part of the individual for whom they care (Melville et al., 2011).

### **3.5.6 The Influence of Programs and Social Opportunities**

**Facilitators.** Enrollment in programs was an important facilitating factor for the physical activity of participants in this study. This finding is supported by previous research, as programs have been reported as being vitally important to the lives of adults with ID, for physical activity and more (Burk & Sharaievska, 2017). Programs provide important opportunities to socialize, which has been cited as one of the most important facilitators to participating in physical activity (Burk & Sharaievska, 2017). Because adults with ID have limited social networks (Amado, Stancliffe, McCarron, & McCallion, 2013), programs can often be the primary source of socializing with those who are not a part of their family. Therefore, even though physical activity was identified by participants as being an important part of day programs, it was clear that participants primarily enjoyed being with friends and meeting new people at the programs they attend, indicating that the social aspect of programs was what was most meaningful to them. The finding of the importance of socializing has been seen in previous research (Bossink et al., 2017) and is the reason why program developers should consider making socializing opportunities fundamental to the design of physical activity programs for this population. Doing so may help to broaden the social support networks of adults with ID,

which may lead to even more opportunities to learn about and access other leisure-time and physical activities.

**Barriers.** Participants in the present study described an enthusiasm to attend their day program(s). The availability of programs that these participants can access and attend on a regular basis is a reflection of major progress in the realm of disability rights and funding in Ontario and Canada. However, there were some participants who expressed that they rely mainly on their program(s) to be active, and do not participate in regular physical activity in other ways. Relying on a day program for physical activity is not inherently negative, but there is still a risk of extended time spent in sedentary pursuits when not attending the program. For example, Hsieh et al. (2017) found that not attending a day program was associated with increased sedentary time. In contrast, Oviedo, Travier, and Guerra-Balic (2017) were unable to find a correlation between day program attendance and higher levels of physical activity. More research is warranted to determine if day program attendance is correlated with physical activity level, as findings have been mixed (Hsieh et al., 2017; Oviedo et al., 2017).

### **3.5.7 The Influence of Unrealized Barriers**

Participants in this study made little to no mention of some of the most salient barriers known for this population, such as financial constraints or lack of community support, and the large majority did not perceive their dependency on caregivers as being a barrier (Bodde & Seo, 2009; Bossink et al., 2017). This is consistent with a study by Mahy et al. (2010), who concluded that the exclusion of these topics was likely due to the limitations related to ID. There is evidence which indicates that adults with ID may have

some challenges in identifying some barriers, which, in itself, is a barrier; if a person cannot perceive, recognize, or understand a barrier, it is difficult for them to address it.

A number of participants referred to physical activities in which they no longer take part, instead of discussing current physical activity. Caton et al. (2012) described a similar phenomenon in their study, in which adult participants with ID described their physical activity in the past tense. The authors wrote that, because of this, “there were reasons to suggest that the activities may not be regular or especially active” (p. 254). In line with this interpretation, it is likely that there is limited physical activity currently happening in the lives of participants in the present study, based on how often they spoke about past physical activity. Future research might consider exploring the reasons why adults with ID can sometimes seem to discuss the past instead of the present, as it could be a reflection of a lack of current physical activity, but may also be a result of their intellectual processing and conception of time (Owen & Wilson, 2006).

There were some participants who were able to identify why they stopped certain activities, such as a coach discontinuance or personal disinterest, while other participants simply said, “I’m not sure the reason why I stopped” or “I don’t know, ask my mom”. Statements like this exemplify the stark differences between adults with ID and adults with TD; adults with TD generally understand why they do or do not participate in activities, whereas some adults with ID in this study appeared to not know the reasons. For example, some participants had difficulty with recognizing that their ceased elementary and secondary school physical activity was at least somewhat linked to the fact that they had aged out of schooling. Instead, those participants displayed a tendency to ascribe their cessation of gym class-based physical activity to their individual

preferences. This indicates a difficulty in identifying external, more abstract barriers, such as their own age precluding them from having the same opportunities they once had.

The theme, *Not Recognizing or Understanding Barriers* relates to both internal and external processes that can lead adults with ID to not have a full comprehension about reasons for participating or not participating. Participants not being able to identify the reasons for physical activity cessation during the focus group may be a reflection of limitations in memory recall (Owen & Wilson, 2006). However, it is also plausible that not knowing might relate to not having been privy to the reasons why they ceased participating, as a result of not being made a part of the decision-making process (Bergström et al., 2014; Taylor, Cobigo, & Ouellette-Kuntz, 2019). It is not uncommon for others to make decisions for adults with ID (Bergström et al., 2014). As previously discussed, parents assume major influence over the physical activity of adults with ID and this can oftentimes include making decisions on their behalf instead of allowing their adult children to decide on their own activities more independently (Bodde & Seo, 2009). It is therefore important that adults with ID be provided opportunities to learn about healthy choices, and that parents be given information and guidance on how to best provide support to their adult children to be physically active and make those choices on their own (Bodde & Seo, 2009; Caton et al., 2012).

The concept of promoting knowledge and choice among adults with ID also opens up a new avenue of discussion, whereby self-determination becomes a more frequently-applied and prioritized concept for adults with ID. Self-determination manifests as the ability, autonomy, and freedom to be informed of choices, make decisions, advocate for oneself, assert oneself, and have definitive control over selecting one's own activities

(Brown & Brown, 2009; Wehmeyer, 1998). There was a participant in the present study who expressed a desire for deciding her own activities instead of her parents deciding for her, essentially expressing a desire for self-determination. However, she went on to admit that she would not be physically active at home if it were not for her parents “bugging” her to do so. In this case, self-determination presents as a barrier to being active, due to an apparent lack of interest in, or prioritization of, physical activity. In contrast, another participant explained that she did not enjoy team sports, and said that she preferred horseback riding, explaining “It’s more me.” She further explained that she horseback rides regularly. In this instance, it seems that choosing her own activity presented as a facilitator. With the understanding that self-determination can pose as both a barrier *and* facilitator to physical activity, these participant descriptions are examples that act to demonstrate why self-determination should go hand-in-hand with health knowledge and practical and emotional support: so that adults with ID can be encouraged to make healthy decisions, autonomously. In addition to being knowledgeable about self-determining health-promoting activities, research has shown that caregiver encouragement of self-determination is related to enhanced awareness, attention, learning, self-image, motivation, and assertion on the part of the individual with ID (Brown & Brown, 2009). Therefore, when opportunities are presented to adults with ID to exercise self-determination, in an informed and adequately-supported way, they are more involved in their own activities, and can reap the benefits of both increased physical activity *and* enhanced independence. Bodde and Seo (2009) and Frey et al. (2005) write that, even if adults with ID do not make the correct or healthy decisions, they should at

least have the freedom to make those decisions on their own, just like the freedom that is afforded to adults without ID.

### **3.6 Strengths and Limitations**

This study had several strengths. As adults with ID are often excluded from research that is about them (Iacono, 2006; Spassiani, Parker Harris, & Hammel, 2016), it was meaningful that these participants were given the chance to have their views represented as the sole focus of investigation. The recruitment of participants was strengthened by partnering with community organizations, as they provided efficient access to an established group of participants in a setting that was familiar to them. The inclusion of nine females and four males in the sample was not representative of the demographics of the wider adult ID population, wherein males are more likely than females to be diagnosed with ID (Boat et al., 2015). However, this may add to the study, as it represents a greater female perspective.

As with all research, this study also had its limitations. Burk and Sharaievska (2017) stated that the comprehension abilities of participants with ID can mean that questions can be misunderstood or misinterpreted, and this could have influenced the way participants perceived and responded to the interview questions. This is often why proxy reporters are included alongside adults with ID in research. However, piloting the interview guide with a small group of adults with ID allowed the principal investigator to reflect on and adjust the phrasing and sequencing of the questions to elicit more complete answers. Regardless, individuals with ID, irrespective of abilities and limitations, should have the opportunity to participate and have a voice in the research that concerns them, and this study was able to deliver that opportunity.

Unfortunately, due to the nature of working within the ‘real world’, and due to an emphasis on inclusion, there was an overflow of participants in one of the focus groups (n=10), compared to the other (n=three). The principal investigator was able to develop rapport with the first group of participants more than the second, and this could have had an impact on the willingness of the participants in the less-familiarized group to feel comfortable to share their experiences during the focus group. However, these issues were addressed by extending the duration of the focus groups. This ensured that each participant of the first had a chance to share their insights for every question, and enabled the participants in the second group to become acquainted and more comfortable with the interviewer as time went on.

The locations of the focus groups may be viewed as a limitation. Interviewing participants at, and during, their programs was the most convenient option, but this environmental context might have had an effect on the participants’ topics of discussion, as many participants regularly returned to the topic of their respective programs at which they were being interviewed.

### **3.7 Implications and Future Research Directions**

This study’s findings and discussion led to an identification of gaps in the literature that require further investigation. As it currently stands, there is a noticeable lack of evidence-based and theory-based physical activity intervention studies for adults with ID (Marks et al., 2013). The design of interventions and programs must account for the results of exploratory studies, such as this one, in order to moderate barriers and maximize facilitators. There is also a need to explore theory-driven interventions that are based in educating adults with ID on healthy lifestyles, and to involve the people who

support them, such as parents and paid support staff, in order to achieve a more comprehensive approach to eliciting positive behaviour change (Temple, Stanish, & Frey, 2017).

Future research should also continue to explore and prioritize the perspectives and insights of the primary stakeholders of this type of research, individuals with ID (Eisenberg, Vanderbom, & Vasudevan, 2016). Participatory action research, in which participants are included in and able to provide insight at all stages of the research process, has experienced success with this population, and its continued use will result in enhanced inclusion, and will likely lead to an overall better understanding of the lived experiences of these individuals (Jurkowski, 2008).

In terms of real-world applications, in order to combat the barriers to physical activity through policy, organizations and programs should hire staff who are knowledgeable of and dedicated to promoting physical activity (Cartwright, Reid, Hammersley, & Walley, 2016; Temple & Walkley, 2007). With further regard to policy, organizations that serve adults with ID should take concrete steps in developing more user-friendly and accessible guidelines and registration protocols to make it easier for adults with ID and their parents and caregivers to take advantage of programs (Samuel, Hobden, LeRoy, & Lacey, 2012).

Finally, it is important to understand that, due to the heterogeneity of the ID population, combined with the differences in resource availability, population density, and structural factors between geographical regions, facilitators and barriers can be different for different ID populations. Therefore, physical activity organizations and programs that intend to implement physical activity opportunities should investigate the

facilitators, barriers, and needs that are specific to ID populations and geographical regions (Taliaferro & Hammond, 2016).

### 3.8 Conclusion

The trend of low physical activity in adults with ID has long been known, but the reasons for this trend warrant further exploration. Recent research attention has been paid to exploring facilitators and barriers that influence physical activity in this population. This type of research is essential for increasing physical activity participation. It not only provides a foundation for more intervention-based research to build upon, it also has the potential to act as a sort of checklist for effectively and successfully actuating physical activity in this population. This present study adds to the current literature and has the potential to improve 1) caregiver support approaches, 2) physical activity and health-promotion programs, interventions, and policies, and 3) future research, all of which will hopefully lead to effective improvements in physical activity participation in adults with ID.

The thematic findings of this study reveal a variety of factors that help to facilitate physical activity, as well as factors that act to hinder it. Facilitator themes that emerged in this study include those occurring in the *individual*, *support*, *program*, and *resources* domains. Barrier themes that emerged include those occurring in the *internal* and *external* domains, as well as *not recognizing or understanding barriers*. The importance of this type of research is predicated on the fact that not only are facilitators and barriers identifiable, they are also *modifiable* (Bodde & Seo, 2009), meaning that they can be changed, improved, removed, and applied as is required, to suit the needs of the population being investigated. This study has met its aim of exploring the facilitators and

barriers that influence physical activity, as experienced and perceived by adults with ID.

The findings confirm some already-known facilitators and barriers, and also add new information to the literature. Research must continue to explore the influences of physical activity for this heterogeneous, marginalized population, and apply these findings in the real world, in order to address low physical activity levels and improve the fitness and health of this population.

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## **CHAPTER 4. CONCLUSIONS**

## **4. Conclusions**

This thesis consists of an introduction, a literature review, a manuscript, and a conclusion. The Introduction (Chapter 1) provided a brief summary of the topic and introduced the scope and aims of this thesis. The Literature Review (Chapter 2) included a discussion on facilitators and barriers to physical activity that has been identified in past research, as well as covered the historical, societal, and etiological aspects of ID, and the population's health status and physical activity levels. The main component of this thesis was the Manuscript (Chapter 3), which collected and analyzed primary qualitative data of participant perspectives and experiences of the influences of their physical activity. This Conclusions chapter (Chapter 4) accomplishes the following: provides an overview of the topic of the facilitators and barriers to physical activity, highlights the key points from the literature review, summarizes the manuscript's results, and offers recommendations for future research and applications.

### **4.1 Overview of the Background and Purpose**

Intellectual disability (ID) is a type of neurodevelopmental disorder that is characterized by limitations in intellectual and adaptive functioning, with an onset during developmental years (American Association on Intellectual and Developmental Disabilities, 2010; Batshaw, Roizen, & Lotrecchiano, 2013; Tassé, Luckasson, & Schalock, 2016). Adults who have ID tend to experience generally poorer physical and mental health in comparison to their peers with typical development (TD) (Cooper et al., 2015). They experience considerably higher rates of obesity, Type 2 diabetes, arthritis, cardiovascular disease, and mental illness (Bielska, Ouellette-Kuntz, & Hunter, 2012; Krahn & Fox, 2014; Reichard, Stolzle, & Fox, 2011), all of which have been evidenced

to be prevented, alleviated, or improved through health-promoting behaviours, including physical activity (Krahn & Fox, 2014; Krahn, Hammond, & Turner, 2006). In fact, regular participation in physical activity is considered to be one of the most important aspects of a healthy lifestyle, as it is protective against preventable diseases, improves health and fitness, and leads to prolonged life expectancy (Tremblay et al., 2011; Warburton, Nicol, & Bredin, 2006). However, research conducted with this population has consistently revealed that they engage in very low levels of physical activity, usually not enough for the maintenance of good health and fitness (Dairo, Collett, Dawes, & Oskrochi, 2016; Finlayson et al., 2009; Frey, 2004).

The low physical activity levels of adults with ID have been attributed to a myriad of challenges that are largely unique to this population (Bodde & Seo, 2009; Bossink, van der Putten, & Vlaskamp, 2017). Unlike adults with typical development, adults with ID face a complex set of challenges that can interfere with their ability to become and stay physically active. Between increased support needs, dependency on others, and increased rates of physical disability, in addition to individual preferences and motivations (Anderson et al., 2013; Bossink et al., 2017), this population faces an extensive set of barriers that stand in the way of being adequately active. As institutional living has been replaced by community living, adults with ID live in less-stringent, less-structured, and more-independent accommodations, which means that they face both increased responsibility over their own health-promoting activities, and increased environmental barriers to participating in them (Bodde, Seo, & Frey, 2009; de Winter, Bastiaanse, Hilgenkamp, Evenhuis, & Echteld, 2011). As a result, the population has generally participated in lower levels of health-promoting behaviours (Stancliffe & Anderson,

2017) and experienced higher rates of preventable disease (Bartlo & Klein, 2011).

However, in spite of these drawbacks, the benefits of community living include increased social connectedness, enhanced time and attention from support persons, declines in challenging behaviour, and increases in activity choice, which have all been shown to culminate in an overall higher quality of life (Lemay, 2009; Spreat & Conroy, 2002).

In the province of Ontario, there are approximately 67,000 adults with ID (The Institute for Clinical Evaluative Sciences, 2013), many of which are situated within the Greater Toronto Area (GTA). Research taking place in the province has revealed that a significant number of adults with ID depend on and utilize health care services at disproportionately high rates (Ouellette-Kuntz et al., 2005), which is at least partially due to their high rates of preventable conditions (The Institute for Clinical Evaluative Sciences, 2013). However, greater health promotion efforts, such as physical activity, can translate to improved health and may lead to reduced service utilization and expenditures (The Institute for Clinical Evaluative Sciences, 2013), thereby making health-promoting initiatives of considerable interest to wider society.

The investigation of the facilitators and barriers to physical activity has been recognized by researchers as an important precursor to the development of programs, interventions, and policies that aim to effectively enhance physical activity participation, for both those with ID and those without (Brooker et al., 2015; Seefeldt, Malina, & Clark, 2002; Shibata, Oka, Harada, Nakamura, & Muraoka, 2009; Temple, 2007). Therefore, the facilitators and barriers that were identified by participants in this study can be used in conjunction with previous research to develop effective strategies to increase the physical activity participation of adults with ID.

## 4.2 Theoretical Framework and Methodology

The literature review of this thesis found that adults with ID are disproportionately excluded from research that concerns them (Horner-Johnson & Bailey, 2013), even when they are the primary stakeholders, so the manuscript of this thesis provided the opportunity for adult participants with ID to share their experiences, insights, and opinions, as the sole focus of the study. The interpretivist and transformative paradigms (worldviews) jointly made up the theoretical framework upon which the qualitative research from this thesis was designed. The intent of the investigation was to not only gain further understanding of the facilitators and barriers to physical activity, but to also do so in a way that represented the subjectivity of participant experiences, and empowered the participants of this marginalized population to use their voices. Therefore, the principal investigator interpreted the data with an appreciation that facilitators and barriers to physical activity are subjective, consist of many variables, and are foundations for change (Creswell & Poth, 2018). The study's theoretical framework aligned with its use of the phenomenological approach, which aimed to capture the "universal essence" of the participants' lived experiences with physical activity (Creswell & Poth, 2018, p. 75). Focus groups, consisting of adults who are well-acquainted with one another, were in further alignment with this study's theoretical framework because they allowed participants' contributions to be validated by their peers (Abbott & McConkey, 2006), which is not something that is possible in individual interviews.

### **4.3 Findings in the Context of the International Classification of Human Functioning, Disability, and Health**

The findings from the thesis manuscript are evocative of the International Classification of Human Functioning, Disability, and Health (WHO-ICF) model, developed by the World Health Organization (2002), which would frame ID as an outcome of interactions between (a) a person's intellectual and adaptive limitations, and (b) contextual factors (i.e. personal, environmental, and social). The themes of the present study, which emerged as a variety of internal and external facilitators and barriers, reflect the participants' views that their physical activity is influenced by both themselves and their outer world, in both positive and negative ways. Thus, programs and interventions that aim to improve physical activity in adults with ID must effectively account for the influences within the individuals *and* in the environment with which they interact, aiming to enact change in *all* contexts (i.e. personal behaviour, environmental accessibility, social support, and policy).

### **4.4 Implications and Applications**

In a 2009 systematic review paper, Bodde and Seo assert, "Without first addressing modifiable environmental and social barriers, tackling the personal, motivational, or cognitive-emotional barriers would be futile." (p. 58). Therefore, strategies that intend to increase physical activity engagement in this population should prioritize the modification of external influences, before trying to change individual behaviour, such as reducing program enrollment cost before addressing an individual's low motivation. Moreover, the strategies based in addressing environmental or social influences are more likely to reach a greater number of adults with ID, compared to

individual interventions, such as through policy and large-scale health promotion efforts (Bodde and Seo, 2009), which reinforces their precedence.

#### **4.4.1 Supporting the Supporter**

Research shows that adults with ID are more likely to be active when their parents and caregivers are involved and knowledgeable, and this can only be achieved by ensuring that parents and caregivers are provided help and guidance themselves (Melville et al., 2011). This introduces the concept of ‘supporting the supporter’, whereby physical activity strategies should be designed to alleviate their stresses and barriers, to educate them, and to include them. For example, local day programs that offer physical activity for adults with ID could connect with secondary school boards, which could then connect with parents of adolescents with ID, in order to enhance information dissemination to those who are about to transition out of schooling and into adulthood, where there may not be any day-time options to supersede school. In this way, parents would become informed about program options instead of the alternative, which would be seeking out options by themselves, or relying on word-of-mouth recommendations. As another example, a yoga program could be designed to include parents and caregivers, which would benefit both individuals with ID and the people who support them. Additionally, for parents who are older, busy, or experiencing burnout, a day program could offer free transport to and from the facility, which would alleviate the stress associated with transport- and time-management that parents and caregivers often experience. These are all practical examples of how the physical activity of adults with ID could be facilitated by providing support to the supporter.

#### 4.4.2 Programs and Policies

The participants in this study also regularly expressed the positive influence that programs had on their physical activity. Results relating to programs were especially important to this study because of the fact that the participants were recruited from them, which provided unique insight into what participants liked and did not like about them. Notably, participants cited social opportunities as an important reason for attending programs, which is not unexpected, as previous research has found that social engagement and a sense of camaraderie are significant facilitators to being active (Bossink, van der Putten, & Vlaskamp, 2017; Taliaferro & Hammond, 2016). Therefore, programs that prioritize socializing and foster social networks have the potential to effectively elicit physical activity participation, as adults with ID express more interest in being active when they are accompanied by friends. While there are currently a number of recreational programs in the GTA that successfully incorporate physical activity *and* socializing opportunities, the ultimate aim should be to expand these programs and make them more available, more affordable, better staffed, and more research-informed.

Policy, although not discussed by participants in this study, represents the highest level at which the results could be applied, as it affects a great amount of people at once (Bodde and Seo, 2009). Governments, agencies, organizations, and programs are governed by a set of policy guidelines that regulate the actions of the people within them. If policies were developed to more effectively incorporate and prioritize physical activity, it is more likely that the employees and volunteers that are mandated by these guidelines will incorporate and prioritize physical activity in the lives of the adults with ID whom they support and attend to. For example, participants in this study spoke highly of the

volunteers and staff that ran their programs, so if more organizations mandated the hiring of staff with physical activity education or experience, it is more likely that they would implement activities that have physical elements. As another example, federal, provincial, and municipal governments might consider creating permanent positions on public health boards for intellectual disability-specific health professionals, which would provide a representative for this population's problems at the highest levels of policy and impact. Policies guide the actions of the people and organizations who provide services to adults with ID, so implementing positive change at the policy level could most effectively result in positive change at the individual level.

#### **4.4.3 Self-determination, Support, and Education**

Many of the findings on facilitators and barriers presented in the manuscript were consistent with the literature, such as the individual influence of personal preference, motivation, and injury, as well as the environmental influence of parents and caregivers, programs, and transportation. However, a more unique barrier emerged, labeled *Not Recognizing or Understanding Barriers*, which represented the difficulty that participants had in identifying some of the barriers to their physical activity. Two possible explanations were proposed: intellectual limitations may have made it difficult for participants to understand, recall, or articulate concepts, and/or there may have been a lack of information provided to participants about why they did or did not participate in certain activities. It is very likely a combination of the two explanations, since it is true that adults with ID face difficulties in understanding and recalling complex concepts (American Association on Intellectual and Developmental Disabilities, 2010), *and* that they are commonly excluded from the decisions made about their own activities

(Bergström, Elinder, & Wihlman, 2014; Cartwright, Reid, Hammersley, & Walley, 2016). Such a finding suggests that a lack of knowledge is derived from both the individual and the environment, which is particularly interesting because it may indicate two things: (1) adults who may be less intrinsically interested in being physically active should be given ongoing support and health-promotion education in order to overcome low motivation or disinterest, and (2) adults with ID should be provided the opportunities to exercise self-determination over their own activities. For those who carry the belief that increased independence could mean decreased physical activity, it is important to note that self-determination and increased autonomy have been reported in past research as *increasing* the likelihood of adults with ID to participate in physical activities (Bergström et al., 2014; Bossink et al., 2017). Therefore, is it worthwhile for adults with ID to take part in planning their own activities. Ultimately, even if they do not make the healthy decision to be active, they should at least be afforded the freedom to make that decision autonomously, because the same freedom to make an unhealthy decision is afforded to adults without ID (Frey, Buchanan, & Sandt, 2005).

Research shows that health literacy is generally low in adults with ID, which has amounted to a lower level of engagement in disease-preventing, health-promoting activities (Caton et al., 2012; Cocks, Thomson, Thoresen, Parsons, & Rosenwax, 2018; Marks, Sisirak, & Hsieh, 2008). However, it is conceivable that when health promotion education and prioritization is accompanied by self-determination and ongoing practical and motivational support, it may be more likely that these adults will make healthier decisions because (a) they will understand the health benefits and consequences of the activities they take part in, and (b) they will feel supported and empowered to be in

control of their own activities. Increased autonomy, support, and knowledge have the potential to lead to increased participation in health promotion activities (Kuijken et al., 2016), and an example of this ‘formula’ takes form in a program called *Healthy Athletes*. This program was developed by Special Olympics to offer free health screenings to all registered athletes, and includes an element of health promotion education. The goals of the health promotion portion of this program are as stated: “encouraging and enhancing healthy behaviors and improving self-efficacy and self-advocacy” (Special Olympics Canada, n.d.). Given that this type of health-promotion education is not something that is generally otherwise offered to adults with ID once they exit secondary school, a program such as this may be quite impactful on physical activity levels and other health behaviours. Therefore, it may be constructive to invest in developing and disseminating more of these programs.

In summary, the findings of this thesis' manuscript, in the context of the supporting literature, point to the need for policies, programs, interventions, and other strategies that effectively utilize facilitators and circumvent barriers in order to successfully increase physical activity participation in adults with ID. Future research should build upon these findings to continue to gain knowledge about how to address the problem of low physical activity levels in this population.

#### **4.5 Recommendations for Future Research**

The findings identified in the manuscript of this thesis suggest a number of areas that warrant further investigation. For one, although the area has grown rapidly over the past decade, there is still a need to explore the facilitators and barriers to physical activity. Due to the specificity of environmental contexts and the heterogeneity of adults

with ID, any interventions, programs, and policies that are developed to increase the physical activity of this population might find it worthwhile to identify the specific physical activity influences that are experienced by the specific population for which they are intended. In addition, the differences in facilitators and barriers experienced between various sub-populations of adults with ID needs more research. Future studies can add to the ID physical activity literature by investigating the differences along the urban-rural divide, among accommodation types, among caregiver types, among different levels of ID, between men and women, between adults who are active and non-active, and between adults enrolled in physical activity programs and adults who are not. This study was unable to report on the level or type of ID of the participants, but Bossink et al. (2017) have expressed a need for researchers to do so, in order to more easily compare and contrast the differences in facilitators and barriers among the various ID levels.

Due to the prominence of parents in the findings of this study as the primary supporters of physical activity, and due to their appearance as both positive and negative influences, it is important that intervention studies are designed to include parents and caregivers. In this way, researchers can better understand the role that parents and caregivers play in physical activity behaviour, which can lead to the development of more effective physical activity interventions (Stanish & Frey, 2008; Temple, Stanish, & Frey, 2017).

The finding of participants having difficulty recognizing or understanding barriers needs further exploration, as the scope of this thesis could not allow for it. Future researchers might consider investigating if the phenomenon is generalizable to the wider adult ID population, and the ways in which a lack of realization of barriers affects their

physical activity. It is also important to determine if the causes of this barrier are intrinsic to the individual's limitations or if it is an outcome of being excluded from decision-making, or if it derives from both. In order to gain clearer understanding of the "I don't know" theme found in the present thesis study, researchers could explore the perspectives of parents, caregivers, and support staff, who may have better insights into why the participants lack knowledge of barriers. The causes of this phenomenon might also be explored through observational studies, such as instrumental case studies, which employ intensive and detailed analysis of individual people, in the context and environment of the phenomenon under investigation, over a prolonged period of time (Creswell & Poth, 2018). Observing individuals in this way could reveal the capacity and involvement that adult participants with ID have in determining and controlling their own physical and leisure activities in their day-to-day lives.

A major gap in the area of health promotion for this population lies in the lack of translation from research to practice (Bartlo & Klein, 2011). A 2018 scoping review by Pitchford, Dixon-Ibarra, and Hauck revealed that only 8% (n=29) of studies in this area were concerned with the direct application of interventions for improving physical activity, and that only 1% (n=5) of studies were concerned with the study of dissemination and feasibility of evidence-based interventions. This area of research is expressly important for the ID population because most health promotion public strategies are not targeted toward or based on research that involved them, so they are not necessarily effective for them (Emerson & Hatton, 2014). Based on these gaps, there is a call for an increase in intervention studies, which must make use of the exploratory

studies such as this one, in order to advance knowledge translation and information dissemination.

Lastly, one of the most important kinds of research for marginalized populations such as this one is participatory action research, which is a type of research method that allows for the participants to be involved in planning and conducting the study, expanding their role from subject to research partner (Bergold & Thomas, 2012; Creswell & Poth, 2018). This type of research method benefits people with ID by emphasizing self-determination (Bergold & Thomas, 2012) and providing them the opportunity to influence research, which is not commonly granted to adults with ID. The research itself would also benefit from increased involvement of adults with ID because it would allow researchers to gain a different perspective of the problem under investigation, reduce any power imbalances that may otherwise exist, and interpret information differently (Bergold & Thomas, 2012). Conducting more participatory action research with this population benefits both the research field and the adult ID population, as it would be a step toward inclusion and the promotion of self-determination in research.

#### **4.6 Conclusion**

This thesis addressed the issue of facilitators and barriers to the physical activity of adults with ID. The literature review detailed the relevant research that has previously taken place on the subject, while the manuscript addressed the gap in the literature by seeking out the views of adults with ID who live in the GTA; to our knowledge, there have been no similar studies previously conducted in this region. This study added to the literature in other ways by including adults with ID as the sole participants, recruiting

adults from physically active day programs, and strengthening the female voice by including a larger proportion of females than males.

Overall, the findings from this study suggest that there are a variety of facilitating and hindering influences to the physical activity of adults with ID. The exploration of facilitators and barriers is an important type of research because it recognizes that physical activity, and the factors that influence it, can be modified, and can therefore be improved (Bodde & Seo, 2009). Interventions and programs that aim to increase physical activity levels should be developed based on the knowledge of facilitators and barriers, and should be appropriately modified based on the needs of specific ID populations. Research that focuses on enhancing physical activity participation can have a major impact on the physical and mental health of adults with ID, so it is important that researchers continue to investigate how physical activity can be made more accessible for this population.

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## **CHAPTER 5. APPENDICES**

**Appendix A. Certificate of Approval from the University of Ontario Institute of  
Technology Research Ethics Board**

*Date:* March 11, 2019  
*To:* Meghann Lloyd  
*From:* Ruth Milman, REB Chair  
*File # & Title:* 15240 - [FULL BOARD] Exploring the barriers and facilitators to physical activity for adults with intellectual disabilities  
*Status:* **APPROVED**  
*Current* March 01, 2020  
*Expiry:*

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Notwithstanding this approval, you are required to obtain/submit, to UOIT's Research Ethics Board, any relevant approvals/permissions required, prior to commencement of this project.

The University of Ontario, Institute of Technology (UOIT) Research Ethics Board (REB) has reviewed and approved the research study named above to ensure compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2 2014), the UOIT Research Ethics Policy and Procedures and associated regulations. As the Principal Investigator (PI), you are required to adhere to the research protocol described in the REB application as last reviewed and approved by the REB. In addition, you are responsible for obtaining any further approvals that might be required to complete your project.

Under the Tri-Council Policy Statement 2, the PI is responsible for complying with the continuing research ethics reviews requirements listed below:

**Renewal Request Form:** All approved projects are subject to an annual renewal process. Projects must be renewed or closed by the expiry date indicated above ("Current Expiry"). Projects not renewed 30 days post expiry date will be automatically suspended by the REB; projects not renewed 60 days post expiry date will be automatically closed by the REB. Once your file has been formally closed, a new submission will be required to open a new file.

**Change Request Form:** If the research plan, methods, and/or recruitment methods should change, please submit a change request application to the REB for review and approval prior to implementing the changes.

**Adverse or Unexpected Events Form:** Events must be reported to the REB within 72 hours after the event occurred with an indication of how these events affect (in the view

of the Principal Investigator) the safety of the participants and the continuation of the protocol (i.e. un-anticipated or un-mitigated physical, social or psychological harm to a participant).

**Research Project Completion Form:** This form must be completed when the research study is concluded.

Always quote your REB file number (**15240**) on future correspondence. We wish you success with your study.

Sincerely,

Dr. Ruth Milman  
REB Chair  
[ruth.milman@uoit.ca](mailto:ruth.milman@uoit.ca)

Emma Markoff  
Research Ethics Assistant  
[researchethics@uoit.ca](mailto:researchethics@uoit.ca)

*NOTE: If you are a student researcher, your supervisor has been copied on this message.*

## Appendix B. Letter of Permission from Program A

**From:** [REDACTED] <[REDACTED]@[REDACTED]>  
**Sent:** February 19, 2019 10:23 AM  
**To:** Shannon Lucas <[REDACTED]@uoit.ca>  
**Subject:** RE: Following up - Physical Activity Focus Group Study

Hi Shannon,

I hope you are well! [REDACTED] and I had a chance to sit down and Friday and go through your email, thank you so much for taking the time to answer all of our questions in detail, we really appreciate it. We are very excited to work with you.

*As the Senior Coordinator of the [REDACTED] program at [REDACTED], I give permission to Shannon to conduct research with service users of the [REDACTED] Adult Day program.*

If possible, I would love for you to come in so we can meet in person briefly to discuss next steps moving forward to ensure success and smooth implementation. Please let me know a day and time that works for you!

If you have any questions or need anything else at this point, please let me know!

Take Care,

[REDACTED]

## Appendix C. Letter of Permission from Program B

**From:** [REDACTED] <[REDACTED]@[REDACTED]>  
**Sent:** February 23, 2019 3:01 PM  
**To:** Shannon Lucas <[REDACTED]@uoit.ca>  
**Cc:** Meghann Lloyd <[REDACTED]@uoit.ca>; Robert Balogh <[REDACTED]@uoit.ca>  
**Subject:** Re: Following up - Physical Activity Focus Group Research Study

Good afternoon Shannon,

Please find my letter of approval attached. Let me know if you need anything else and what the next steps are.

Thanks,

[REDACTED]

[REDACTED]

February 23, 2019

Shannon,

After reviewing the outline of your research project concerning the barriers and facilitators to physical activity for adults with intellectual disabilities, I agree to allow you to contact [REDACTED] program participants. I will use your parameters to identify individuals that might be a good fit and will get their permission to allow for this contact to happen.

Regards,

[REDACTED]

[REDACTED]  
Executive Director  
[REDACTED]

## **Appendix D. Invitation and Study Information Email for Program Directors**

Version date: 2019-02-28

**Title of Research Study:** Exploring the barriers and facilitators to physical activity for adults with intellectual disabilities

**Principal Investigator:** Shannon Lucas, BHSc, MHSc candidate

**Contact email, number:** [REDACTED]@uoit.ca, [REDACTED]-[REDACTED]-[REDACTED]

This study has is currently under review by the University of Ontario Institute of Technology Research Ethics Board [REB file #15240] and is awaiting approval. If you have any questions about participant rights, please contact the Research Ethics Coordinator at 905-721-8668 ext.3693 or [researchethics@uoit.ca](mailto:researchethics@uoit.ca).

---

### **What is this study about?**

I am inviting adults with intellectual disabilities to participate in focus group interviews to discuss their experiences with physical activity and the factors that influence their ability to be active on a regular basis. I will be asking participants questions about the kind of physical activity they do, how often they participate in it, and other questions relating to their opportunities to be active.

### **What is the significance of this study?**

The knowledge gained from this study has the potential to improve the physical activity of adults with intellectual disabilities by shedding light on the difficulties and successes they experience with participating in sport and exercise. The findings of this study may help to inform physical activity approaches/strategies at the individual, family, organization, community, and/or government levels.

### **What are the procedures of study?**

I will be audio-recording the focus group discussion to be able to later transcribe and analyze it for prominent/repeating themes. Any information shared by participants will remain anonymous. There is a rigorous consent process which involves having the researcher meeting with each participant to explain the study, answer any questions they

might have, ensure they understand that participation is voluntary and can be withdrawn at any point, and obtain consent/assent. On the day of the focus group, the participants will be re-explained the study and their rights.

### **What will be your role in this study?**

If you think taking part in this study might be worthwhile for some of your adult service users, your role would include providing me with the contact information of those individuals who you feel might have the ability and interest to participate in a focus group discussion. I am recruiting individuals who meet the following inclusion criteria:

- a service user of your organization
- 18-65 years of age
- is no longer a high school student
- can verbally communicate, well enough to answer questions and speak in a small group setting with peers (these are likely adults with mild intellectual disabilities who require a relatively low level of support in their daily living and will understand their rights and the basic elements of the study.)

I ask that you use your knowledge and judgement to help with screening for potential participants. Your role would also include reaching out to service users who might fit the inclusion criteria (or to their substitute decision makers, if applicable) and obtaining their permission to have me contact them. If your service users give their permission for you to send me their contact information, I will contact them to explain the study. You will be CC'd on these emails so that you can know that I have reached out to them. I will not share service users' contact information with anyone or use their contact information to solicit anything beyond this study. If you prefer, I can also drop into the program, introduce myself, explain the study, and provide a paper invitation handout.

### **How can participants join the study?**

For individuals who have replied to me expressing their interest, and if they meet the inclusion criteria, I will schedule an individual meeting with them in-person before the day of the focus group to describe the study and obtain consent/assent. If a service user

has the capacity to consent, I will be obtaining their consent. If a service user requires a substitute decision maker, I will be obtaining their assent as well as consent from the substitute decision maker. This will all be explained to potential participants/substitute decision makers.

Thank you,

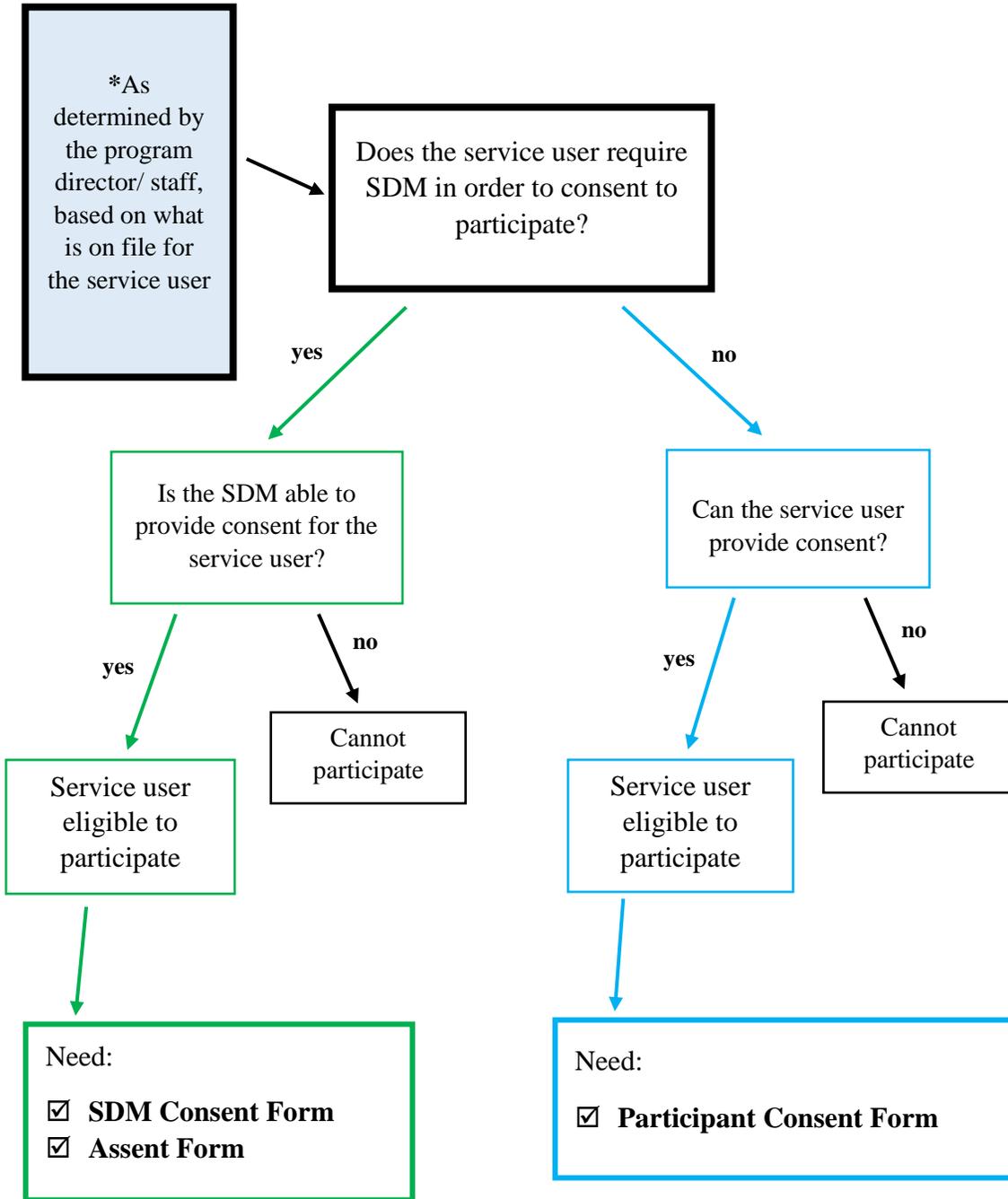
*Shannon Lucas*

*Master's of Health Science candidate*

*University of Ontario Institute of Technology*

## Appendix E. Decision Tree – Consent vs. Assent vs. Cannot Participate

Version date: 2019-02-28



**Service user:** potential participant, adult with intellectual disability

**SDM:** substitute decision maker

## Appendix F. Participant Consent Form

Version date: 2019-02-28

**Title of Research Study:** *Exploring the barriers and facilitators to physical activity for adults with intellectual disabilities*

**Researcher:** Shannon Lucas, BHSc, MHSc candidate

**Institutional affiliation:** University of Ontario Institute of Technology

**Phone:** ■-■-■

**Email:** ■■■■■@uoit.ca

### **Use of this form** (for the principal investigator):

This form exists in the situation that an adult participant with an intellectual disability is determined to **not** have the capacity to consent. When this is the case, two procedures become necessary: 1) a form for assent for the participant, and 2) a form for consent for the substitute decision maker. **This form is for obtaining assent from an adult participant with intellectual disability to participate in this research study.**

### **Why am I being asked to be a part of this research study?**

You are invited to participate in a research study called *Exploring the Barriers and Facilitators to Physical Activity for Adults with Intellectual Disabilities*. This study has been reviewed the University of Ontario Institute of Technology Research Ethics Board [REB file #15240] and originally approved on March 11<sup>th</sup>, 2019.

You are being asked to take part in this research study because we are trying to learn more about the physical activity of adults with intellectual disabilities. I am asking you to be in the study because you can help me learn more about the types of sport and exercise you do and the things that make it hard, and easy, for you to stay active. I will be asking you questions in a focus group.

### **What is a focus group?**

A focus group is where people sit in a circle and answer questions about a topic. You do not have to be in this focus group if you don't want to.

### **If I join the study what will happen?**

If you choose to be in the study,

- You will be in the focus group for 30 minutes to 1 hour.
- Your voice will be recorded during the focus group.
- I will ask you questions about the kinds of exercise and sports you do.
- You can answer my questions any way you want.
- Your name will not be shown to anyone after you leave here today.
- Your guardian/ parent/ friend/ family member can be waiting outside the room/ waiting nearby/ just a phone call away.

### **Will the study help me? (Benefits to participating)**

You will not benefit directly from participating in this study. This study might help me understand things about sports and exercise and might help other people like you someday.

### **Will any part of the study hurt? (Risks to participating)**

No, there is nothing dangerous about being a part of this research study. You might feel uncomfortable sitting for a long time but you can get up and stand or walk around whenever you feel like it. If you feel nervous or shy about answering questions, you don't have to talk. If you want to leave the room you can do that too.

### **Who will see the information collected about me? (Privacy and Confidentiality)**

The information collected about you during this research study (like your name, phone number, and answers to my questions) will be kept safely locked up. I will not write your name in my written research paper. I will instead use what's called a "pseudonym", which is like a "code name", so that no one can know you were in this study.

Nobody will know what you tell me in the focus group except for myself and the other people in the focus group. It is important that you don't tell anyone what the other people in the focus group say, so that their participation is also kept private. Everything you say will be kept private, unless you tell me that someone is hurting you or hurting someone else.

### **Where will you keep my private information? (Storage of Data)**

Only myself and my two supervisors will be able to see your personal information. I will save all of your signed documents on a password-protected computer, in a private file. I will destroy any paper copies. I will transfer the voice recording of the focus group onto a computer, then I will immediately delete it from the device. I will delete all of your personal information 5 years after the focus group.

### **Do I have to be in the study? (Right to Withdraw)**

You do not have to be in this research study. It's up to you. No one will be angry or upset if you don't want to do this study. All you have to do is tell me you don't want to participate anymore.

During the focus group, if you feel uncomfortable, stressed, or embarrassed when I am asking questions, you do not have to answer them. You can leave

whenever you want. You will still get a Tim Horton's gift card if you leave the study. If you do leave the study, anything you say will not be used in my study. The latest possible date to withdraw your contributions to the focus group will be September 1<sup>st</sup>, 2019.

**Does my guardian/parent(s) know about this study?**

This study was explained to your guardian/ caregiver/ parent(s)/ substitute decision maker and they said that we could ask you if you want to be in it. You can talk this over with them before you decide.

**What if I have questions?**

If you have any questions you can contact the researcher, Shannon Lucas, at [redacted]-[redacted]-[redacted], or [redacted]@uoit.ca. If you have any questions about your rights as a participant in this study, please contact the Research Ethics Coordinator at 905-721-8668 ext. 3693 or [researchethics@uoit.ca](mailto:researchethics@uoit.ca).

<b>Assent</b> <i>(for the principal investigator to complete):</i>		
I have discussed this research study with _____ using language which is understandable and appropriate for the participant. I believe that I have fully informed him/her of the nature of the study and its possible risks and benefits. I believe the participant understood this explanation and assents to participate in this study.		
<input type="checkbox"/> <b>Check this box if you understand the study and agree to participate.</b>		
_____ Researcher obtaining assent	_____ Signature	_____ Date

## Appendix G. Participant Assent Form

Version date: 2019-02-28

**Title of Research Study:** *Exploring the barriers and facilitators to physical activity for adults with intellectual disabilities*

**Researcher:** Shannon Lucas, BHSc, MHSc candidate

**Institutional affiliation:** University of Ontario Institute of Technology

**Phone:** ■■■-■■■-■■■

**Email:** ■■■■■■■■■■@uoit.ca

### **Use of this form** (for the principal investigator):

This form exists in the situation that an adult participant with an intellectual disability is determined to **not** have the capacity to consent. When this is the case, two procedures become necessary: 1) a form for assent for the participant, and 2) a form for consent for the substitute decision maker. **This form is for obtaining assent from an adult participant with intellectual disability to participate in this research study.**

### **Why am I being asked to be a part of this research study?**

You are invited to participate in a research study called *Exploring the Barriers and Facilitators to Physical Activity for Adults with Intellectual Disabilities*. This study has been reviewed the University of Ontario Institute of Technology Research Ethics Board [REB file #15240] and originally approved on March 11<sup>th</sup>, 2019.

You are being asked to take part in this research study because we are trying to learn more about the physical activity of adults with intellectual disabilities. I am asking you to be in the study because you can help me learn more about the types of sport and exercise you do and the things that make it hard, and easy, for you to stay active. I will be asking you questions in a focus group.

### **What is a focus group?**

A focus group is where people sit in a circle and answer questions about a topic. You do not have to be in this focus group if you don't want to.

### **If I join the study what will happen?**

If you choose to be in the study,

- You will be in the focus group for 30 minutes to 1 hour.
- Your voice will be recorded during the focus group.
- I will ask you questions about the kinds of exercise and sports you do.
- You can answer my questions any way you want.
- Your name will not be shown to anyone after you leave here today.
- Your guardian/ parent/ friend/ family member can be waiting outside the room/ waiting nearby/ just a phone call away.

### **Will the study help me? (Benefits to participating)**

You will not benefit directly from participating in this study. This study might help me understand things about sports and exercise and might help other people like you someday.

### **Will any part of the study hurt? (Risks to participating)**

No, there is nothing dangerous about being a part of this research study. You might feel uncomfortable sitting for a long time but you can get up and stand or walk around whenever you feel like it. If you feel nervous or shy about answering questions, you don't have to talk. If you want to leave the room you can do that too.

### **Who will see the information collected about me? (Privacy and Confidentiality)**

The information collected about you during this research study (like your name, phone number, and answers to my questions) will be kept safely locked up. I will not write your name in my written research paper. I will instead use what's called a "pseudonym", which is like a "code name", so that no one can know you were in this study.

Nobody will know what you tell me in the focus group except for myself and the other people in the focus group. It is important that you don't tell anyone what the other people in the focus group say, so that their participation is also kept private. Everything you say will be kept private, unless you tell me that someone is hurting you or hurting someone else.

### **Where will you keep my private information? (Storage of Data)**

Only myself and my two supervisors will be able to see your personal information. I will save all of your signed documents on a password-protected computer, in a private file. I will destroy any paper copies. I will transfer the voice recording of the focus group onto a computer, then I will immediately delete it from the device. I will delete all of your personal information 5 years after the focus group.

**Do I have to be in the study? (Right to Withdraw)**

You do not have to be in this research study. It’s up to you. No one will be angry or upset if you don’t want to do this study. All you have to do is tell me you don’t want to participate anymore.

During the focus group, if you feel uncomfortable, stressed, or embarrassed when I am asking questions, you do not have to answer them. You can leave whenever you want. You will still get a Tim Horton’s gift card if you leave the study. If you do leave the study, anything you say will not be used in my study. The latest possible date to withdraw your contributions to the focus group will be September 1<sup>st</sup>, 2019.

**Does my guardian/parent(s) know about this study?**

This study was explained to your guardian/ caregiver/ parent(s)/ substitute decision maker and they said that we could ask you if you want to be in it. You can talk this over with them before you decide.

**What if I have questions?**

If you have any questions you can contact the researcher, Shannon Lucas, at [redacted]-[redacted]-[redacted], or [redacted]@uoit.ca. If you have any questions about your rights as a participant in this study, please contact the Research Ethics Coordinator at 905-721-8668 ext. 3693 or [researchethics@uoit.ca](mailto:researchethics@uoit.ca).

<b>Assent</b> <i>(for the principal investigator to complete):</i>		
I have discussed this study with _____ using language which is understandable and appropriate for the participant. I believe that I have fully informed him/her of the nature of the study and its possible risks and benefits. I believe the participant understood this explanation and assents to participate in this study.		
<input type="checkbox"/> <b>CHECK THIS BOX IF YOU UNDERSTAND THE STUDY AND AGREE TO PARTICIPATE.</b>		
Researcher obtaining assent	Signature	Date

## Appendix H. Substitute Decision Maker Consent Form

Version date: 2019-02-28

**Title of Research Study:** *Exploring the barriers and facilitators to physical activity for adults with intellectual disabilities*

This study has been reviewed by the University of Ontario Institute of Technology Research Ethics Board [#15240] and originally approved on March 11th, 2019.

**Researcher:** Shannon Lucas

**Faculty Supervisors:** Robert Balogh, Meghann Lloyd

**Institutional affiliation(s):** University of Ontario Institute of Technology

**Contact number(s)/email:** [REDACTED], [REDACTED]@uoit.ca

### **Use of this form** (*for the principal investigator*):

This form exists in the situation that an adult participant with an intellectual disability is determined to **not** have the capacity to consent. When this is the case, two procedures become necessary: 1) a form for assent for the participant, and 2) a form for consent for the substitute decision maker. **This form is for obtaining consent from a substitute decision maker to allow an adult with intellectual disability to participate in this research study.**

### **Purpose:**

Regular physical activity is known to play a key role in the maintenance of physical and psychosocial health. However, previous research shows that people with intellectual disabilities have difficulty staying active. The purpose of this research study is to investigate the various factors influencing the physical activity of adults with intellectual disabilities.

### **Procedures:**

The person for whom you are a substitute decision maker is invited to take part in a focus group in which they will be asked a range of questions pertaining to their physical activity and the things that influence it. My goal is to understand factors that make it easy for them to be active (facilitators) and factors that make it difficult (barriers).

The researcher will be audio-recording this focus group interview session so that she can later transcribe the participant's contributions word-for-word, ensuring all data can be

analyzed. The interview will include broad, open-ended questions. It is expected to take approximately 30-60 minutes.

As the substitute decision maker, you are allowed to be present during the focus group. However, because some questions relate to persons who play a role in the participant's physical activity, your presence may influence the answers that they provide. It is for this reason that it is asked that you wait outside the room.

**Potential Benefits:**

The participant will not directly benefit from taking part in this research study. However, the information the participant provides will help to determine the factors that influence the physical activity of adults with intellectual disabilities living in this area. This knowledge has the potential to impact future research and approaches to improving physical activity opportunities for this population.

**Potential Risks or Discomforts:**

There are no foreseeable risks to participating in this study. The information provided by participants will be kept secure and their anonymity will be ensured. Should they feel uncomfortable at any time during the session, they may choose to withdraw from participating. If this is the case, any information they provide will be removed from this study.

**Storage of Data:**

The audio-recorded sessions will be saved and transcribed word-for-word into a word processing file with all identifying information removed (i.e. name, any mention of specific names of other people and places). Once transferred to a secure folder on a password-protected computer, the audio recording will be immediately deleted from the recording device. Any and all identifying and personal information, such as this consent form, will also be electronically saved on a password-protected USB in a locked cabinet, in a locked office, then it will be deleted/destroyed. All participant information will be kept until the completion of the research study up to a maximum of five years. After this time, the data will be appropriately deleted. The only people who will have access to this data will be the researcher and their supervisory committee.

**Confidentiality:**

As stated, any information that is collected will be kept confidential to the full extent of the law. The participant's name will be removed from any data collected. Any written or spoken contributions made to this study will not be shared with, shown to, or sent to anyone else. The information shared during the focus group will be combined with other participants' information, and participants will never be identified in any way if/when the results of this study are published. The only time an exception to confidentiality will be made is if you or the participant tells us that someone is hurting them or someone else, or if they are going to seriously hurt themselves, you, or someone else.



## Appendix I. Participant Demographic Survey

Version date: 2019-02-28

**Name:** \_\_\_\_\_

**Age:** \_\_\_\_\_

**Gender:**  Female  Male

**City/Town of Residence:** \_\_\_\_\_

**How often do you exercise/play sports?**

- Every day
- A few times a week
- Once a week
- Once a month
- Rarely/almost never

**Do you have a job?**

- Yes
- No
- Going to school

**Who do you live with?**

- My parent(s)
- Other family member(s)
- Roommate(s) only
- Roommate(s) with support staff
- Support staff only
- I live by myself
- Other: \_\_\_\_\_

**Where do you live?**

- House
- Apartment
- Condo
- Other:  
\_\_\_\_\_

**What does your neighbourhood look like? (check all that apply)**

- Busy streets (lots of cars)
- Quiet neighbourhood
- Bus route
- Friendly neighbours
- Lots of sidewalks
- Lots of people walking outside
- Parks nearby
- Gyms/ fields/ sports places nearby

## Appendix J. Introduction Script: Day of Focus Group

Version date: 2019-02-28

**\*Make sure audio recorders are recording.**

Researcher:

- Hi everyone. I want to thank all of you for taking part in this study today. As I explained last week, I'm going to ask you some questions. I want to know the things that make it **hard** for you be active. I also want to know the things that **help** you stay active.
- For the next hour, instead of your regular morning chat we're going to be talking about this. I'm going to be asking you some questions and you will take turns answering them. There are no wrong answers. You can tell me about your thoughts, feelings, and experiences with physical activity.
- My friend beside me is Tayler. She's a classmate of mine and she's offered to help me today by taking notes and keeping track of time.
- I have two jobs today. My **first** job today is to ask you all questions and listen to your answers. My **second** job is to make sure that we finish on time. The last thing I want to do is keep you here all day long. So, along the way, if I interrupt you and politely ask to move onto the next person, it's because you did a good job answering and I want to hear from others.
- Now, **your** jobs are just to answer my questions. You are going to take turns answering, and we're going to go in order. When I say your name, that means it's your turn to speak. There are no wrong answers today. I want to hear about what you have to say. If you **don't** have anything to say, you can just say "pass". If you feel uncomfortable answering any questions, or if you can't think of an answer, that's okay. You don't have to answer any questions you don't want to.
- You're allowed to stand up, walk around, stretch, and go to the bathroom. Do whatever you need to do to feel comfy and relaxed. If you want to stop answering my questions, you can. There is no pressure to talk. I want you to do what feels right for you.
- You can leave at any time, for any reason. That is your right. After **I** leave here today and go home, I'm going to type up what you said on my computer and put it in my research paper for my school. If you change your mind and decide that you don't want me to include what you said in my research paper, you have until September 1<sup>st</sup> to contact me and tell me that.

- I am taping our discussion on a few sound recorders, which means it will record your voice and anything you say. It is important to try to speak clearly and to only have one person talking at a time. So, we will take turns answering.
- I will remind you that all of your personal information will be private. Your name and personal information will not appear in my research paper. Also remember that you can't share anyone else's answers with other people outside the group.
- In the end, this group discussion is about being open and being comfortable. I am here to learn about the kinds of things that help you or stop you from exercising and playing sports. I hope that you find the questions interesting and that you leave here today knowing that you helped me and helped my research.
- You also leave here today with a \$10 gift card to Tim Horton's. If you choose to leave and not participate, you will still get a gift card.
- If you have any questions you can ask them whenever you want. Does anyone have any questions right now?

**\*Double-check that audio recorders are recording.**

## Appendix K. Interview Guide

Version date: 2019-03-29

1. I want to know more about you. Tell me about some of your favourite activities and hobbies.
  - *Probe*: free time, during the day
  
2. A) Raise your hand if you like to play sports sometimes?  
B) **Why** do you like to play sports?
  
3. A) Raise your hand if you like to exercise/work out sometimes?  
B) **Why** do you like to exercise/work out?
  
4. **What** or **who** helps you stay active?
  - *Probe*: Is there something that gets you moving or gets you motivated? How do they help you? Who **could** help you stay active/what about other people?
  
5. **Where** do you go to play sports or exercise?
  - *Probe*: Do you have a **favourite place** you go to play sports/be active/exercise?
  
6. **How** do you get to those places?
  - *Probe*: What form of **transportation** do you take to get there?
  
7. What happens when no one can take you to those places?
  - *Probe*: if you don't have someone to take you, do you still go? How do you get there?

8. What makes it **hard** for you to stay active?
  - *Probe:* is there something that stops you from being active? **On days that you are not doing sports or working out, why not?**
  
9. A) Raise your hand if you don't like to play sports sometimes?  
B) **Why** don't you like playing sports?
  
10. A) Raise your hand if you don't like to exercise sometimes?  
B) **Why** don't you like exercising?
  
11. [Some of you already told me about some programs that you attend.] **Why** do you go to those programs?
  - *Probe:* What is **good** about it/What do you **like** about it?
  
12. Last question: Are there physical activities/sports/exercises that you used to do, but stopped doing?
  - *Probe:* **Why did you stop?** What about when you were a **kid or teenager?**

## **Appendix L. Closing Remarks Script: After Focus Group**

Version date: 2019-02-28

Researcher:

- Thank you for such a fantastic discussion! You all did a great job answering my questions. I learned so much about the kinds of physical activities you do and your answers are going to be so helpful in my research project.
- Please remember that I will make sure that all of your personal information will be kept private. And please remember that it is important to make sure that you don't share anyone else's answers with others outside the group discussion today.
- Also remember, if you change your mind about having your answers included in my research project, you can contact me to let me know.
- This marks the end of today's group discussion! Thanks so much for joining me and Tayler today and answering the questions so well. I hope you had a little fun doing this with me! As a further thank you to you all, you each get a Tim Horton's gift card.

**\*Stop audio recorders.**

**\*Hand out gift cards to participants.**

## Appendix M. Thank-you Letter to Program A

Dear [REDACTED], [REDACTED], and [REDACTED] staff and volunteers,

On behalf of myself, my supervisors, and the university, I want to thank you for giving me the opportunity to speak with some of the program attendees and learn more about their experiences with physical activity. As I expressed to you in our early contact with one another, I believe research on this topic is immensely important for everyone, but especially for adults with intellectual disabilities, who may not always have the opportunities required to stay fit. It was a privilege to speak with [REDACTED], [REDACTED], and [REDACTED]. I was afforded a meaningful glimpse into their experiences, and their contributions are invaluable to my study. I hope that they too got something out of the experience.

All members of the [REDACTED] staff that I had a chance to meet were welcoming and accommodating, especially the two young women that sat in on the focus group, as they added a level of comfort to the room that helped the participants feel more relaxed and speak more openly.

[REDACTED], as the program lead, your willingness, enthusiasm, effort, and knowledge were fundamental to the success of this research and I am truly appreciative of you. I wish you all the best in your wonderful career, which found you, as much as you found it.

If you're interested in receiving information about my study following its completion, or if you have any questions, always feel free to contact me. My cell number is [REDACTED]-[REDACTED]-[REDACTED] and you have my email: [REDACTED][@uoit.ca](mailto:[REDACTED]@uoit.ca).

It has been a pleasure working with you all.

Yours gratefully,

Shannon Lucas

*Principal Investigator*

*Master's of Health Science in Kinesiology candidate*

*University of Ontario Institute of Technology,*

*2000 Simcoe Street, North, Oshawa, Ontario*

## Appendix N. Thank-you Letter to Program B

Dear [REDACTED], [REDACTED], [REDACTED], [REDACTED], and all of [REDACTED],

On behalf of myself, my supervisors, and the university, I want to thank you all for playing such an important role in my study. Your willingness, effort, patience, flexibility, and knowledge were fundamental to the success of this research. I am truly appreciative.

It was a privilege to work with the [REDACTED] group, and I am so thankful I was afforded this opportunity to get a meaningful glimpse into their experiences with physical activity. Their contributions are invaluable to my research. I hope that they too got something out of the experience.

If you're interested in receiving information about my study following its completion, or if you have any questions, always feel free to contact me. My cell number is [REDACTED]-[REDACTED]-[REDACTED] and you have my email: [REDACTED]@uoit.ca.

It has been a pleasure working with you all.

Yours gratefully,

Shannon Lucas

*Principal Investigator*

*Master's of Health Science in Kinesiology candidate*

*University of Ontario Institute of Technology,*

*2000 Simcoe Street, North,*

## Appendix O. Confidentiality Agreement for Inter-rater Coder/Research Assistant

Version date: 2019-02-28

**Title of Research Study:** *Exploring the barriers and facilitators to physical activity for adults with intellectual disabilities*

**Research Assistant:** \_\_\_\_\_  
(Your name)

**Principal Investigator:** Shannon Lucas, MHSc candidate

### By signing this form, I agree to the following:

- I understand that all the material I will be asked to record, analyze, and/or transcribe is confidential
- I understand that any digital recordings, data, and transcripts can only be discussed with the principal investigator working on this study and may not be shared with others in any format
- I will not keep any copies of the information nor allow third parties to access them
- I will delete all interview, datasets, and other relevant files from my computer after transcription/use is complete
- I will keep my computer and any datasets and transcripts password protected and secure
- I will maintain the anonymity of all participants involved in this research study
- I will keep any information regarding all participants in this study in the strictest confidence and will discuss any information about the participants only with members of the research group

- SIGNATURE PAGE -

**Title of Research Study:** *Exploring the barriers and facilitators to physical activity for adults with intellectual disabilities*

**I AGREE TO ABIDE BY THE TERMS OF THIS CONFIDENTIALITY AGREEMENT:**

Research Assistant:

\_\_\_\_\_

*Print name*

\_\_\_\_\_

*Date*

\_\_\_\_\_

*Signature*

Principal Investigator (Shannon Lucas):

\_\_\_\_\_

*Print name*

\_\_\_\_\_

*Date*

\_\_\_\_\_

*Signature*

### Appendix P. Codebook with Code Counts

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
<b>ACTIVITY TYPES (FOR CODE COUNTING)</b>				
Leisurely (non-structured)	(For code counting.) Refers to a light physical activity that is done for the main purpose of enjoyment.	n/a	n/a	<b>52</b>
Program-based (structured)	(For code counting.) Refers to a type of physical activity that is organized, including sports or structured in-program physical activities.	n/a	n/a	<b>43</b>
Sedentary (non-structured)	(For code counting.) Refers to a type of activity that is very low in bodily movement and intensity.	n/a	n/a	<b>38</b>
Moderate-to-Vigorous (non-structured)	(For code counting.) Refers to a type of physical activity that is for the purpose of sustaining or improving health and fitness.	n/a	n/a	<b>24</b>
<b>CATEGORY: INDIVIDUAL/PERSONAL (INTERNAL)</b>				
Enjoyment	Refers to enjoying physical activity.	18	0	<b>18</b>
Dislike	Refers to disliking physical activity.	0	8	<b>8</b>
Boring	Refers to the negative feeling of boredom that a	0	2	<b>2</b>

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
	participant experiences when participating in physical activity.			
Too challenging, difficult	Refers to the perception of a physical activity being too difficult.	0	3	<b>3</b>
Preference for light activities over MVPA	Refers to selecting/enjoying lighter, more leisurely activities more so than higher intensity physical activities.	0	15	<b>15</b>
Preference for MVPA over light activities	Refers to selecting/enjoying physical activities more so than lighter, more leisurely activities.	1	0	<b>1</b>
Prioritizing family over physical activity	Refers to a participant ending participation in physical activity for the purpose of wanting to spend more time with family.	0	2	<b>2</b>
'It's more me'	(In Vivo code) Specializing or narrowing to one sport because it feels more suitable for a participant.	1	0	<b>1</b>
Still exercises, but at lower intensity level	Refers to a participant engaging in physical activity, at lower intensities than they previously had.	1	0	<b>1</b>

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
Self-determining activities	Refers to a participant choosing their own activities.	0	2	<b>2</b>
Injury, soreness, condition, not feeling well	Refers to not participating in physical activity due to injuries, health conditions, or not feeling well.	0	7	<b>7</b>
Fitness or health reasons	Refers to being active for the purpose of being healthy and/or fit.	12	0	<b>12</b>
'I wanna be active. I like to be active.'	(In Vivo code) Refers to a desire to be active, for the sake of being active. (This phrasing has a meaningful distinction from "Health or fitness reasons" and "Enjoyment, pleasure")	6	0	<b>6</b>
'Makes me feel good'	(In Vivo code) Refers to a general positive feeling experienced from being active. (This phrasing has a meaningful distinction from "Enjoyment, pleasure" and "Feeling of physical strength".)	3	0	<b>3</b>
Feeling of physical strength	Refers to a participant feeling physically strong due to participating in physical activity.	5	0	<b>5</b>
Mobility walking aid	Refers to a mobility walker as an influencer of physical activity.	1	1	<b>2</b>

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
Competency	Refers to a sense of competency influencing physical activity.	2	0	2
Sense of accomplishment or pride	Refers to a participant having a sense of accomplishment or pride in oneself for being active.	2	0	2
Mood, temporary feeling	Refers to a participant's temporary mood affecting their interest or willingness to be active.	0	2	2
Tiredness	Refers to a feeling of tiredness having a negative influence on being active.	0	2	2
Boredom eliciting participation	Refers to the feeling of boredom as a reason for engaging in physical activity.	2	0	2
Self-motivation	Refers to being internally driven to decide on one's own to participate in physical activity.	1	1	2
Busyness	Refers to the sense of busyness that a participant feels interferes with their ability to be active.	0	2	2
'I like to work hard'	(In Vivo code) Refers to the enjoyment of hard work as a reason to be active.	1	0	1

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
'I wanna do something different'	(In Vivo code) Refers to a desire to end one activity in order to begin another. (This phrasing has a meaningful distinction from "Boredom eliciting participation", "Boring", and "It's more me". Its connotation could be either positive or negative)	.5	.5	<b>1</b>
Trying new things	Refers to participating in new and unfamiliar physical activities.	0	1	<b>1</b>
Preference toward unhealthy habits	Refers to selecting and partaking in less-healthy/unhealthy behaviours.	0	1	<b>1</b>
Negative past experience with PA	Refers to a past experience having negative effects on a participant's willingness/desire to be active in current day.	0	5	<b>5</b>
Apprehensive or fearful of sustaining injury or pain	Refers to a hesitance to participate in physical activity due to fear of getting injured.	0	3	<b>3</b>
<b>CATEGORY: SUPPORTS AND RELATIONSHIPS (EXTERNAL)</b>				
Parent encourages	Refers to a parent encouraging/motivating/guiding the participant in being active.	12	0	<b>12</b>

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
Parent participates	Refers to a parent participating or engaging in physical activity themselves, hence influencing a participant's physical activity.	9	1	<b>10</b>
Parent authority	Refers to a parent controlling, managing, or even restricting the behaviour of a participant.	2	3	<b>5</b>
Parent as health guide or role model	Refers to a parent providing help or role model behaviour as it relates to general healthy living.	2	0	<b>2</b>
Parent manages transportation	Refers to a parent driving a participant to a location where they participate in physical activity, or overseeing responsibilities for other forms of transportation.	12	1	<b>13</b>
Bus transports	Refers to the Durham Transit bus providing transportation to a physical activity-based program.	2	0	<b>2</b>
Bus company policy, challenges	Refers to the Durham Transit bus influencing a participant's ability to attend a physical activity-based program.	0	2	<b>2</b>
Bus waitlist	Refers to having to be placed on a waitlist before	0	1	<b>1</b>

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
	being able to access the bus as transportation to the location of a participant's program.			
Relies on others for transport	Refers to a participant expressing that they depend on other people for travelling to and from places (unspecific to parents).	2	1	3
Hired staff transports	Refers to a hired staff/paid carer driving a participant to a location where they participate in physical activity.	1	0	1
Animal or pet connection, contact	Refers to an animal or pet influencing physical activity.	6	2	8
Friend participates	Refers to a friend's participation that affects the participant's physical activity.	3	1	4
Meeting new people, socializing	Refers to the enjoyment of socializing as being a reason for being active.	3	0	3
Friend encourages or assists	Refers to a friend encouraging/motivating/guiding the participant in being active.	1	0	1
Desire for more friend encouragement	Refers to a desire by the participant to have their	0	1	1

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
	friends engage in physical activity with them.			
Friend cessation	Refers to a friend who has ended their own participation in a physical activity, hence influencing the physical activity of the participant.	0	1	<b>1</b>
Friend's attitude	Refers to a friend's negative attitude influencing a participant's physical activity.	0	1	<b>1</b>
Partner as role model	Refers to a participant's significant other being viewed as a role model.	1	0	<b>1</b>
Using the phone to initiate PA with friends	Refers to a participant calling people to initiate physical activity with them.	1	0	<b>1</b>
Sibling as role model	Refers to a participant's sibling being viewed as a role model.	4	0	<b>4</b>
Sibling participates, encourages	Refers to a sibling influencing a participant's physical activity via encouragement, motivation, guidance, and/or their own participation.	3	0	<b>3</b>
Sibling lives far away	Refers to a sibling's distant living situation	0	1	<b>1</b>

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
	influencing a participant's physical activity.			
Family participates	Refers to a family member (either extended family or unspecified family member) engaging in physical activity.	1	0	<b>1</b>
Coach, sensei drop-out	Refers to an instructor stopping their coaching, therefore affecting the participant's physical activity.	0	1	<b>1</b>
Trainer encourages, motivates, or guides	Refers to a trainer encouraging/motivating/guiding the participant in being active.	1	0	<b>1</b>
Teacher as health guide or role model	Refers to a school teacher providing help or role model behaviour as it relates to general healthy living.	1	0	<b>1</b>
<b>CATEGORY: PROGRAMS (EXTERNAL)</b>				
Program provides PA opportunities	Refers to a program that has been structured/designed to include physical activities.	13	0	<b>13</b>
Program provides social interaction opportunities	Refers to a participant expressing that a program provides them the opportunity to be both active <i>and</i> social.	3	0	<b>3</b>

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
Socializing as the motivator to attend program	Refers to the desire to socialize as the reason for attending a physical activity-program.	1	0	<b>1</b>
Discomfort with other program attendees	Refers to the negative effect that peers and teammates have on a person wanting to participate in a physical activity program.	0	2	<b>2</b>
Friends at program	Refers to having friends at a program.	1	0	<b>1</b>
Friends at program a form of emotional support	Refers to a feeling of comfort due to the emotional support they receive from a friend at a program they attend.	1	0	<b>1</b>
Program provides extraneous experiences	Refers to a physical activity-based program that offers additional opportunities outside the program setting or time.	1	0	<b>1</b>
Program provides classes (that are not PA-based)	Refers to a physical activity-based program that provides a participant with other useful skills and knowledge.	4	0	<b>4</b>
Program regularity	Refers to a program's regularity/frequency.	3	0	<b>3</b>
Program available year-round	Refers to a program being available to a participant throughout the year.	1	0	<b>1</b>

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
Program the preferred place to be active	Refers to a program being the preferred/most-liked location to be active.	4	0	<b>4</b>
Program the only or main place to be active	Refers to a program being a participant's main or only source/location for being active.	0	2	<b>2</b>
Staff participates	Refers to a staff/volunteer participating or engaging in physical activity themselves, hence influencing a participant's physical activity.	1	0	<b>1</b>
Staff encourages or guides	Refers to a staff/volunteer encouraging/motivating/guiding the participant in being active.	2	0	<b>2</b>
Desire for more staff encouragement	Refers to a desire to have receive more encouragement from staff and volunteers at programs.	0	1	<b>1</b>
Staff as emotional support	Refers to a participant's feeling of comfort due to the emotional support they receive from a staff/volunteer at a program they attend.	2	0	<b>2</b>
Program absence	Refers to a participant missing the opportunity to participate in a physical activity at a program due to their absence.	0	1	<b>1</b>

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
Enjoy day program	Refers to a general enjoyment of day programs.	1	0	<b>1</b>
<b>CATEGORY: RESOURCES AND ENVIRONMENT (EXTERNAL)</b>				
Available at-home resources	Refers to physical activity resources and opportunities in the home and in the neighbourhood surrounding the home.	13	0	<b>13</b>
Lack of at-home resources	Refers to not having access to physical activity resources within the home or immediate surrounding neighbourhood.	0	2	<b>2</b>
Walking for transport purposes	Refers to a participant walking for the purpose of getting from one place to another.	2	0	<b>2</b>
Bicycling for transport purposes	Refers to bicycling for transportation.	1	0	<b>1</b>
Weather and seasons	Refers to physical activity being influenced by the weather and seasons.	4	2	<b>6</b>
Outdoor sports field or park	Refers to accessing a sports field as a location for physical activity.	2	0	<b>2</b>
Beach, natural setting	Refers to natural environment influencing physical activity (not weather).	2	0	<b>2</b>

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
Community centre	Refers to accessing a community centre as a location for participating in physical activity.	3	0	3
Gym membership or access	Refers to access to a gym as an influence of physical activity.	6	0	6
Bowling league	Refers to accessing a bowling centre/league as a location for participating in physical activity.	4	0	4
Cottage as PA opportunity	Refers to accessing cottage as a location for participating in physical activity.	2	0	2
Local lodge, bar, club	Refers to accessing a local pub/club as a location to participate in physical activity.	1	0	1
Farm, stables	Refers to a farm as a location for physical activity.	1	0	1
<b>CATEGORY: DIFFICULTY RECOGNIZING BARRIERS (INTERNAL OR EXTERNAL)</b>				
'I'm not sure the reason why I stopped'	(In Vivo code) Refers to a participant not fully understanding/knowing the barriers that are preventing/have prevented them from being active in the way they want to be active. (A participant may	n/a	n/a	3

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
	begin to speculate, but it is clear that they do not know for certain what barriers stand/stood in their way.)			
'I used to' or past-tense	(In Vivo code) Refers to a participant expressing an activity that they used to participate in but no longer do.	n/a	n/a	<b>21</b>
Perception of minimal barriers	Refers to a participant stating that it is easy to stay active.	n/a	n/a	<b>2</b>
<b>UNCATEGORIZED CODES</b>				
Accountability, keeping a commitment	Refers to a commitment to physical activity that a participant has that makes them feel accountable/responsible to attend.	1	0	<b>1</b>
Charity walk	Refers to walking for the purpose of raising money for a charity.	1	0	<b>1</b>
Important PA knowledge or skill (e.g. water safety)	Refers to participating in physical activity for the purposes of gaining new skill or knowledge.	1	0	<b>1</b>
Job incidental physical activity	Refers to accumulating physical activity from doing work during employment.	1	0	<b>1</b>

Code name	Code description	Number of facilitator references	Number of barrier references	Total number of references
PA opportunity no longer available due to aging out	Refers to a participant's age/state of adulthood influencing their ability to participate in physical activities.	0	1	<b>1</b>
Routine, regularity	Refers to the recognition of routines of physical activities.	8	0	<b>8</b>
Cost	Refers to the cost of an activity influencing participation.	0	1	<b>1</b>